

AWARD NUMBER: W81XWH-12-1-0524

TITLE: Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI.

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REPORT DATE: February 2017

TYPE OF REPORT: Final Report

PREPARED FOR: U.S. Army Medical Research and Materiel Command  
Fort Detrick, Maryland, 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;  
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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE February 2017		2. REPORT TYPE Final, Phase 1		3. DATES COVERED 30Sep2012 - 29Nov2016	
4. TITLE AND SUBTITLE Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-12-1-0524	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Denise G Tate, PhD., Lisa DiPonio MD, Edward Rohn PhD., Martin Forchheimer  E-Mail: dgtate@umich.edu				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)  University of Michigan 3003 South State Street Ann Arbor, MI 48109-1274				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)  U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT  Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT Risk factors to bladder and bowel complications suggested associations between neurological status and hemorrhoids and urinary tract infections (UTIs). Chronic constipation was associated with using straining /bearing down as a bowel management method. Lower rates of hemorrhoids were observed among those who used laxatives and /or medications. Those who used intermittent catheterization done by others reported higher rates of UTIs. Frequent complications included UTIs, bladder and bowel incontinence. A trend was observed with those injured 25 years or more having a higher number of complications. There were no differences in bowel complications as a function of military experience. A trend was also observed between quality of life (QOL) and time since injury (TSI). Those with greater TSI reported higher QOL. Studying individual's lives in a narrative format highlighted a number of issues. Using a Response Shift model, patterns of behavioral adaptation reflecting responses to complications were identified. Compared to civilians, more veterans changed their methods of management to solve complications. These decisions were associated with increased satisfaction and fewer complications. Factors influencing positive changes included behavioral changes leading to health adaptations, access to resources such as caregiving, family support and needed supplies.					
15. SUBJECT TERMS Spinal cord injury, veterans, bowel and bladder complications, quality of life.					
16. SECURITY CLASSIFICATION OF: U			17. LIMITATION OF ABSTRACT  Unclassified	18. NUMBER OF PAGES  347	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT  Unclassified	b. ABSTRACT  Unclassified	c. THIS PAGE  Unclassified			19b. TELEPHONE NUMBER (include area code)

## **TABLE OF CONTENTS: FINAL REPORT**

	<u>Page</u>
Front cover.....	1
SF 298.....	2
Table of Contents.....	3
Introduction.....	5
Body.....	6
Year One.....	7
Year Two.....	9
Year Three.....	11
Year Four.....	13
Key Research Accomplishments.....	17
Reportable Outcomes.....	20
Conclusion.....	23
References.....	25
Appendices.....	26
Original Statement of Work.....	27
Personnel Report.....	30
Operations Manual.....	31
Coding Schemes and Manuals.....	150
Focus Group Protocols.....	204
Caregiver Interviews Summary Report.....	210
Focus Group Summary Reports.....	225
Supporting Data.....	236

Sample Attributes.....	237
Means and Standard Deviations for Study Measures.....	239
Bladder and Bowel-Quality of Life Matrix.....	240
Response Shift-Quality of Life Matrix.....	254
Response Shift-Quality of Life Thematic Analysis.....	265
Complications Matrix.....	266
Caregiving Matrices.....	286



## **INTRODUCTION**

Persons with SCI have associated neurogenic bladder and bowel dysfunction, making this aspect of their care important to providers, researchers, and especially to those with SCI, their families and caregivers. While progress has been made in the area of bladder management after SCI, little has been done with respect to the psychosocial consequences of neurogenic bladder and bowel and their impact on quality of life (QOL). Two aims guided this investigation. The first was to identify risk factors associated with neurogenic bladder and bowel medical and psychosocial complications after SCI. The second aim was to determine the influence of bladder and bowel management, complications and psychosocial and behavioral factors on QOL. By evaluating a distinct military cohort (N=22), we were able to examine differences across these aims. We also looked at the differing perspectives of persons with SCI and caregivers. A mixed method, multiple source approach to data collection and analysis was used to address the aims. Qualitative interviews were conducted with persons with SCI (N=40) and caregivers (N=20). Additionally, 18 persons (12 SCI and 6 caregivers) participated in focus groups. Qualitative analysis includes the construction of matrices to display coded text of narratives, facilitating thematic analysis and pattern finding, and mapping of text to the proposed conceptual model. These were supplemented by quantitative analyses of the many factors influencing QOL, as well as comparative triangulation between qualitative and quantitative findings. Proposed treatment recommendations are discussed based on our findings.

**Keywords:** Spinal cord injury, neurogenic bowel and bladder, bowel and bladder complications, methods of managing neurogenic bowel and bladder, hemorrhoids, bowel incontinence, bladder incontinence, urinary tract infections, constipation, psychosocial and behavioral factors, mixed methods, qualitative methods, coping and adaptation, sexuality and relationships, catheters, intermittent catheterization, quality of life, decision making, response shift, caregivers.

## **BODY**

### **Project Major Goals as Stated in the Statement of Work (SOW)**

The project goals were reflected in its plan of operation to ensure proper accomplishments of activities related to the SOW and aims, as described above. Six tasks were originally proposed in the SOW (see Appendix) to be conducted during the four years of the project, including a one-year extension and a two-month extension (2012-2016).

- 1.1. Administrative tasks included *infrastructure* related tasks such as hiring and recruiting personnel, establishing accounts and appointments, hiring contractual services (transcriptions) and engaging consultants (Duggan, Roller, Lequerica). In addition, *regulatory and coordination/collaboration* tasks included approval of IRBs at both organizations (University of Michigan and Ann Arbor VA) and IRB-mandated training certificates. For scientific guidance, an advisory board was established to discuss progress. All proposed administrative tasks were completed during Years 1 and 2 of the project with the exception of project reports and IRB continuing renewals, and IRB-mandated training renewals, which continued through the duration of the project.
- 1.2. Research Design tasks included a review of measures to be used, pilot testing assessments for data collection, and development of databases: quantitative and qualitative. There were no changes made to the design with exception of providing somewhat less structure to qualitative interviews, as suggested by members of the advisory board.
- 1.3. Recruitment-related tasks included developing a plan for recruitment, implementing the plan across sites, scheduling interviews and focus groups.
- 1.4. Data Collection and Data Processing tasks included training interviewers, developing interview guides and a data collection procedures manual, entering data, completing transcripts of all interviews and focus groups audio files.
- 1.5. Data Analysis and Evaluation tasks included qualitative analysis of textual data, quantitative analysis of measures data, as well as mixed methods analyses and data triangulation, comparing qualitative and quantitative data. Coding schemes were developed and revised. Emergent patterns across the entire dataset were identified.
- 1.6. Dissemination and Data Sharing tasks included development of dissemination products such as presentations and publications and sharing the data with specific audiences, including professional meetings, stake holders, and the advisory council.

### **Major Project Accomplishments Under these Goals**

Project accomplishments are discussed below, summarized by project year. Only selected major accomplishments are described to avoid duplicating the content of annual and quarterly reports. The text that follows is thus a summary of these accomplishments by major activities, specific objectives or aims, significant results, and other achievements. Dates are identified in terms of continuous months (1- 50).

## Year 1 (10/1/2012–9/31/2013)

### Major Activities

*Administrative tasks* completed during this period included the establishment of project infrastructure, hiring personnel, designing and providing training and orientation for staff, investigators and consultants (Months 1-12). Dr. Rohn was successfully recruited (Month 8) to serve as the project coordinator and oversee the qualitative analyses of the project with consultants Duggan and Lequerica. Post-doctoral fellow Nevedal assisted with training of personnel and conceptualization of the research methodology (Months 1-6). Contractual arrangements were completed with a transcription service for UMHS (Month 10). However, VA transcriptionist services were not available. A work plan was developed by the PI Tate (Months 2-3) and coordination between the two main sites, the University of Michigan Health Systems (UMHS) and the Ann Arbor Veterans Administration (VA) and site PIs (Tate and DiPonio) was established, allowing for training and certification at the VA, IRB preparation, and recruitment (Months 1-12). While the UMHS IRB was quickly approved, the VA IRB process involved considerable extra work and time to be approved in order to ensure the safety and security of the data to be collected. Final approval from the Department of Defense, CDMRP program came in July of 2013 (Month 10) to begin project research activities.

*Research activities* involved the development of interview guides by Tate, Nevedal and Rohn (Months 3-10), reporting forms (Months 5-9), the development of a data collection procedures manual (Months 10-11), testing and refining measures to be used (Months 4-9), establishing a quantitative database using REDCap (Months 8-10), and training interviewers (Months 7-12). Interview guides were implemented to establish some standardization in data collection but also allowing for flexibility depending on issues raised by participants. The interview protocols were piloted with four volunteers who met recruitment criteria. From these pilot interviews, Refinements were made to the interview guides based on pilot experiences. a preliminary coding scheme was developed and refined after discussions with co-investigators and consultants (which would be finalized in Month 18, see Year 2 for more details).

The project methodology entailed a mixed-methods, multiple-source approach to data collection and analysis. The text of transcribed interviews was segmented into lines of text and entered into NVivo10 software for analysis. Codes were then applied to the narrative text. These codes were then retrieved for purpose of analysis. The development of matrices of data addressed the two aims of the project. Only aim 2 was addressed during Year 1 through the development of a brief matrix to depict our preliminary data. Quantitative data was obtained across six measures: Quality of Caregiving Measure (QCM), Spinal Cord Injury Lifestyle Scale (SCILS), Bowel and Bladder Treatment Index (BBTI), Behavioral Adherence Assessment of Bowel and Bladder Treatment (BAABBT) and several PROMIS and SCI-QOL short forms (see Appendix for complete measures). The purpose of these quantitative analyses was to confirm patterns derived from the qualitative analyses by comparing and contrasting these data as well as to provide supplemental information on topics such as methods of bowel and bladder management.

*Recruitment* included sending letters and announcements about the study to potential participants following IRB approval (Months 11-12). Six UMHS SCI participants and one UMHS caregiver participant were successfully recruited and interviewed during Year 1 of the project (Month 13). Recruitment was slow to start due to IRB delays and obtaining final approval for the project to start.

*Data Collection and Data Processing* began with SCI participants at UMHS (Month 12). All interviewers (qualitative and quantitative) were trained with joint training between qualitative interviewers conducted to ensure consistency in the interview process. Four pilot transcripts were completed at UMHS. Coders began training and underwent an inter-reliability test based on pilot data to determine consistency in coding (Months 11-12). This coding scheme was then applied to the six UMHS SCI participants' transcripts (Month 12).

*Data Analysis and Evaluation Activities* consisted of reviewing initial data from interviews (Months 11-12), questionnaires and transcripts for quality and accuracy, reviewing data analysis methods including coding and matrix development to identify data patterns and trends. Sufficient data was not yet available for more formal analysis.

*Dissemination and Data Sharing* included two poster presentations accepted (Month 11) for the International Spinal Cord Society on the development of interview forms and a review of preliminary findings on the effects of bowel and bladder dysfunction on QOL, as suggested by the early interview data.

### Specific Objectives or Aims

There were no findings directly related to aim 1 of the project but some preliminary findings were obtained in relation to aim 2 which focused on the impact of bladder and bowel complications to QOL. These findings, discussed below, were presented as the second poster presentation listed above. In addition, to avoid overlap with another project, the objective about the use of a bladder and bowel diaries using a Day Reconstruction Method (DRM) to collect data on daily life context to capture episodes of incontinence was discontinued since it became part of a larger study (Tate PI), funded by the National Institute on Disability and Rehabilitation Research, which had been submitted earlier.

### Significant Results: An Assessment of Needs

A number of themes were identified by SCI participants in relation to challenges faced due to neurogenic bowel and bladder management and complications and how these affect QOL. These included issues of environmental accessibility; physical functioning and ability to take care of one's bowel and bladder functions; barriers to societal participation and employment; and time management and planning required to address one's bladder and bowel functions. Sexuality concerns and the challenges of establishing and maintaining intimacy were also reported. Social activities were limited by the lack of accessible restrooms and toilet facilities, both in public and private places. Differences were not yet identified between veteran and civilian respondents.

### Other Achievements

*A Collaborative Platform for Research:* Stronger collaborations were developed with researchers from the VA and the Department of Urology at UMHS which allowed the investigators to have access to multiple brainstorming meetings regarding recruitment, IRB and data collection procedures. This exchange of viewpoints and information provide a solid planning base for future discussions regarding the project methodology, initial findings and dissemination products, such as joint presentations and publications.

## Year 2 (10/1/2013–9/31/2014)

### Major Activities

*Administrative Activities* included 1) establishing a solid mechanism for working collaborative with the Ann Arbor VA to include IRB approvals, certification of credentialing and data confidentiality, recruitment and interviewing (Months 13-19); 2) recruiting, hiring and training new research staff for transcribing VA interviews (Sarah Steffens BS (Months 15-16) and for coding interviews (Roxane Madrid MA and Emily Zafiroff BA (Months 13-16); and 3) hosting our first advisory council meeting on March 21<sup>st</sup> 2014 (Month 18). Additional activities included IRB renewals and report preparation and submission. Advisory council members recommended the completion of a comprehensive review of the literature in order to refine the coding scheme and to identify areas or gaps in the literature to be added to the coding scheme; to compare our quantitative findings with those of national samples, and to target focus groups with episodic experiences of bowel and bladder complications impacting QOL. A complementary review of the literature was completed by Rohn and Tate (Months 19-21) to identify other possible issues to include in the coding scheme (this literature was also included in presentations made during this year). The result was a focus on issues of coping and adaptation with respect to neurogenic bowel and bladder after SCI using a response shift conceptual model developed by Schwartz et al.<sup>1-4</sup> Similarly, to the extent that data was available, researchers compared the project quantitative findings with those from the SCI Model Systems (SCIMS) and other national databases (Months 20-23). Work published by Cameron et al.<sup>5</sup> analyzing data on bladder from the SCIMS database provided a framework for comparisons. Because her study focused on older individuals with SCI, these comparisons were not all relevant. On the other hand, not much published and public information is available on SCI veterans with respect to bowel and bladder. Lastly, recruitment for focus groups took into consideration those who had encountered significant episodes of complications (Months 19-24).

*Research Activities* focused heavily on advancing data collection. Refinements to the use of the interview guides were implemented to allow for greater flexibility in response to issues raised by participants. A great deal of effort was focused on the development of a more-robust coding scheme for data analysis. A coding manual was prepared (Months 15-18) and discussed among investigators, staff, consultants and advisory board members. Discussions of the coding scheme with investigator Kratz (Months 15-18) expanded the coding scheme to include five distinct group of factors (physical, psychological, social, environmental and personal) affecting bowel and bladder outcomes and ultimately, QOL. The result was our final coding scheme (see Appendix).

*Recruitment* – In spite of some initial difficulties, recruitment of UM participants was completed across all cells while VA participant recruitment was 80% completed during Year 2. Similarly, caregivers' recruitment for UM was also completed while 60% of caregivers of VA participants were successfully recruited. In addition to physician' clinics and registries, recruitment through the Michigan Paralyzed Veterans of America (MPVA) proved to be effective and helpful.

*Data Collection and Data Processing* – A total of 45 (75%) interviews were completed in Year 2, including all UM participants' interviews. All transcripts were checked for accuracy, cleaned and loaded into NVivo 10 for coding. The final coding scheme was applied to all completed interviews, including those coded to the previous scheme (Month 23). All quantitative data collection was also completed during Year 2. Information was entered into a REDCap database where quality control was conducted for missing information and errors in data entry (Months 20-23). Data was then entered into a SPSS database for analyses (Month 24).

*Data Analysis and Evaluation Activities* – A total of 28 transcripts were coded using the new coding scheme in Year 2. A meeting among investigators and consultants in Month 14 focused on planning data analysis using a mixed method approach. The team began identifying preliminary data patterns and themes (Months 18-24). The project was positively evaluated by its advisory council during its meeting in March of 2014; methodological recommendations made were implemented accordingly. Consultant Duggan prepared a first matrix focusing on narrative related to QOL outcomes (Month 19; see Supporting Data) while consultant Lequerica presented to the group on his recommendations about mixed methods (Month 21).

*Dissemination and Data Sharing* – A presentation on project methods and preliminary findings was presented at MPVA for veterans with SCI by Study Coordinator Rohn (Month 18). Two poster presentations were made (Month 13) at the 52<sup>nd</sup> annual meeting of the International Society of Spinal Cord by the PI.

### Specific Objectives or Aims

While some of the preliminary quantitative analyses focused on Aim 1 related to risk factors such as demographics and methods of management used, most qualitative analyses conducted focused on identifying themes related to QOL (Aim 2).

### Significant Results

A few significant results were observed from quantitative analyses conducted during Year 2. Time since injury (TSI) was found to be significantly correlated with QOL ratings ( $r=.50$ ;  $p<.001$ ) and satisfaction with social roles and activities ( $r=.33$ ;  $p<.038$ ). Similarly, those with greater TSI mentioned more frequent episodes of complications, such as UTIs ( $p<.04$ ) and bladder incontinence ( $p<.08$ ). A significant association ( $p<.008$ ) was found between TSI and neurological classification, with 83% of those with incomplete paraplegia being in the most recent TSI cohort.

### Other Achievements

A coding manual was finalized and compiled for the study.<sup>6</sup>

### Year 3 (10/1/2014–9/31/2015)

#### Major Activities

*Administrative Activities* - Usual activities related to project infrastructure and coordination among sites, regulatory and financial monitoring activities took place during Year 3. Greater emphasis on project evaluation and planning were part of these activities. The team met in Month 25 to review remaining tasks and discuss a timeline. The focus was on completing focus groups and conducting data analysis. Two of our team members ended their appointments during Year 3: Ms. Steffens had finalized transcription on 20 interviews and reviewed all 40 transcripts to remove identifying information and correct inaccuracies; and Ms. Madrid completed her coding work on her portion of the transcripts. Dr. Kratz also left the project because an increase in her own research project commitments made her unable to continue to participate.

*Research Activities* – Investigators, consultants and project staff continued to refine the application of the coding scheme to best fit the conceptual framework of the project. Topic specific matrices were generated to best capture our results and existing data (Months 27-36). This included a 1) complications matrix; and a 2) response shift matrix including QOL data.

*Recruitment* – Individual participants' recruitment was completed and 18 focus groups participants were also successfully recruited during Year 3 (12 SCI participants and 6 caregivers). Tables showing the attributes of the entire SCI and caregiver samples are included below (see Supporting Data).

*Data collection and Data Processing* – This year saw completion of all data collection activities. Focus groups were conducted, audio recorded, and transcribed. SCI focus groups participants were divided into two groups that balanced sex, level of injury, time since injury, and veteran status, capturing the diversity of our sample. Preliminary assessment of the transcripts revealed some broad topical patterns. Topics from SCI participants ranged from definitions of QOL, expectations about caregiving, general concerns about bowel and bladder management, struggles with sexuality, the sense of manhood, negative emotions in relation to struggles with disability, and current quality of life issues. Caregivers discussed being a family caregiver and the impact on their health, expectations, secularity and intimacy as well as relationships. Social and economic concerns were also prevalent in both groups, including interruptions to expected life trajectories, retirement, financial security. These activities occurred from Months 25-30.

*Data Analysis and Evaluation* – All transcripts were completed and reviewed for accuracy (Month 36) and loaded into NVivo 10 during Year 3. Coding was completed by Month 36 for all individual interviews. Application of the final coding scheme was subject to careful inter-rater reliability checks at regular intervals. Mixed methods analysis including identifying common patterns and themes across the narrative data and triangulation with complimentary measures were completed. As mentioned under research activities, data analysis focused on complications and QOL including response shift as a conceptual model for coping and adaptation in relation to complications and its effects on QOL.

*Dissemination and Data Sharing Activities* – An abstract was accepted for an oral presentation by the PI on findings examining the associations of response shift stages and QOL at the 2015 Annual Conference of the International Society for Quality of Life Research. Plans for dissemination sharing also include two manuscripts to be prepared by the PI on the presentation above and study coordinator on issues of resilience among women with SCI (pending

submission). An article by Nevedal and other project team members on women with SCI and their bowel and bladder issues was published by the journal "Disability and Rehabilitation".<sup>7</sup>

### Specific Objectives or Aims

During this period, we continued refining quantitative analysis on risk factors including methods, demographics, complications (Aim 1), and QOL using PROMIS and SCI-QOL especially. The bulk of the analysis, however, focused on Aim 2 and on the qualitative data distilled into matrices according to key topics such as Response Shift (signaling adaptation to bladder and bowel changes) and QOL (Months 32-36). Some preliminary triangulation of this data was also completed (Aims 1 and 2).

### Significant Results

The most common method of bowel management was digital stimulation (65%) followed by digital evacuation (47.5%), rectal suppositories (40%) and laxatives and other oral medications (37.5%). For bladder management, intermittent catheterization by self was the most frequently used method (57.5%). No differences were noted in relation to methods used as a function of military experience. There was also no difference in bowel complications. While those in the military were less likely to experience UTIs (50% vs. 77.8%) these results were not statistically significant ( $p=.07$ ). No difference in satisfaction with life were observed as a function of military experience. Response shift ratings were significantly associated with QOL ratings ( $p<.006$ ) with those who were more likely to make adaptive changes reporting higher QOL. Some preliminary triangulation analysis showed that the rate of complications was higher when reported through qualitative interviews versus the Bowel and Bladder Treatment Inventory (BBTI). Differences in methods of data collection and on timeframe for questions being asked may have account for these differences and lack of significant correlations ( $r=.18$ ;  $p=.27$ ). However, when dichotomizing the BBTI into those with less than four complications and 4-5 complications, and comparing these same groupings with data from the qualitative interviews, the relationship was much stronger, with 70% agreement ( $p=.017$ ).

### Other Achievements

An additional manuscript was prepared for submission in a special issue of the *Archives of Physical Medicine and Rehabilitation* on bowel management and complications (published in Year 4). While the focus of this manuscript was on neurogenic bowel, data analysis was performed using data from a larger quantitative study being conducted by the SCI Model Systems project. Literature reviewed included articles found when completing a review for this DoD study.

Two additional invited presentations were made by the PI at the Canadian Physical Medicine and Rehabilitation Society meeting and the International Collaborations in Repairs Discoveries in Vancouver, Canada. Each focused on QOL in bowel and bladder management, with one focused on patient reported outcomes and the other on implementing QOL measures in SCI clinical settings. While these did not focus on the qualitative analysis, they included qualitative quotes from this project. In addition, a presentation and two posters were also presented at the 2015 American Spinal Injury Association (ASIA) meeting, focused on measuring bladder and bowel management. One focused on cross-cultural comparison of QOL measures. A third poster on patient-provider alliance was also presented.



## **Year 4 (10/1/2015–9/30/2016) plus two additional months (10/1/16–11/30/16)**

### **Major Activities**

*Administrative Activities:* The project was extended for an additional year due to late start time following delays from IRBs and especially in establishing a working infrastructure with the VA, which required not only IRB approval (delayed for several months) but also training and certification of our team (Rohn, Roller) to be able to recruit and interview VA participants and caregivers. Ms. Zafiroff completed her work, finalizing the coding of the entire dataset and assisting with qualitative analysis, and left the project for another position in Year 4. Ms. Madrid returned temporarily, and assisted with the literature review for one of the publications, completing her task in March of 2016 (Month 42). Another short extension of two months (Months 49-50) was approved for the entire project and remaining staff to accommodate an in-progress project review presentation on October 25-26 at Fort Detrick, Maryland.

*Research Activities:* The team met several times with consultant, Duggan, to discuss final data analyses (Months 40-42). The focus was on caregiver data. Consultant Roller prepared reports based (Month 45-47) on her observations of focus groups (both SCI and Caregiver) and Caregiver interviews, based on her review of all transcripts (see Appendix for reports).

*Recruitment* – There were no recruitment activities during Year 4, as data collection was completed in Year 3.

*Data Collection and Data Processing* – There were no data collection activities during Year 4. All caregivers' transcripts were coded (Months 40-42). The two additional coding activities begun in Year 3 were completed (response shift and complications) for data presentations, involving a finer-grained application of more-specific codes to capture relevant data. A third coding activity was begun and completed on caregiving for both SCI and Caregiver participants. This resulted in additional matrices (see Supporting Data) further facilitating analysis and generating findings (discussed in below and in Reportable Outcomes).

*Data Analysis and Evaluation* – A matrix was developed summarizing caregivers' issues and topics. All quantitative data were imported into SPSS for data analysis. These data can then be compared to the project qualitative data. All measures were scored and measures of central tendency established for the sample. Extensive work was done to combine the qualitative data sources into a single, final database. Summary variables were created and quality control checks were conducted. Analyses focused on response shift data in relation to complications and QOL. A number of additional triangulation analyses were conducted comparing reported rates of complications, differences in coping responses to complications and subsequent the impact on QOL, and the validity of using QOL using different measures. Analyses were also conducted comparing participants who did and did not receive caregiver services. Preliminary reports of focus group findings were prepared by Consultant Roller and analyzed by PI Tate and Study Coordinator Rohn. Preliminary focus group findings helped to confirm and enrich understanding of key topics including decision-making, QOL, bladder and bowel management, and sexuality.

*Dissemination and Data Sharing Activities* – Several presentations were made during this period. In August, Study Coordinator Rohn made an oral presentation at the Paralyzed Veterans of America 2016 Summit in Orlando, Florida. His presentation focused on response shift patterns among veterans with SCI. See reference list for all presentations described here. In September, The PI presented a poster on complications with bowel and bladder comparing veterans and civilians with SCI data (Month 48) at the 55<sup>th</sup> Annual Meeting of the International Spinal Cord

Society (ISCoS) in Vienna, Austria; 2) Both the PI and Study Coordinator Rohn presented at the 93<sup>rd</sup> Meeting of American Congress of Rehabilitation Medicine meeting in Chicago, IL in October of 2016 (Month 49). The PI presented a poster on complications among veterans comparing their decision making process to solve these complications with strategies used by civilians while Study Coordinator Rohn presented his work on response shift and quality of life, including differences in response shift leading to changes in perceived QOL, in turn suggesting implications for approaches to clinical interventions. Also on October 25 (Month 49) the PI presented project findings at the CDMRP In-Progress Review for the Spinal Cord Injury Program (SCIRP) in Fort Detrick. Lastly in November (Month 50), the PI was invited to be the keynote speaker at the Australian and New Zealand Spinal Cord Society (ANZSCoS) Annual Meeting in Adelaide, Australia. The presentation entitled “A Theory for Everything from Coping to Shifting” described the conceptual model of this project and shared data about the various stages of response shift, actions to address complications and impact on QOL. Three publications focusing on complications, response shift and resilience are currently at various stages of preparation. Two will reflect data presented at these meetings.

### Specific Objectives or Aims

Both Aims 1 and 2 were the focus of data analyses and presentations during Year 4. Understanding the mechanisms by which participants were able to appraise their related complications, elicit adaptive responses and make decisions leading to greater QOL was central to our data analyses and resulting findings.

### Significant Results

In relation to response shift, those exhibiting full response shift were more likely to discuss behavior and awareness driven themes and none raised themes of resignation and despair. Those mentioning behavior driven themes tended to report the highest QOL while those using social comparison and resignation responses were the least likely to be employed suggesting coping through accommodation processes. No differences were as a function of military service, receipt of caregiver assistance, neurological status or demographic factors. In general, responses to complications helped participants move towards normalizing their experiences with SCI and neurogenic bowel and bladder. Many demonstrated clear agency in devising solutions for management challenges and complications. There were frequent references to pain, and those with incomplete injuries tended to experience more urinary leakage overall. Finally, VA participants relied heavily on surgical interventions to manage their bladder and bowel dysfunction.

In addition to reported rates of complications using qualitative and quantitative analyses, triangulation analyses were performed related to response shift scores and QOL rating and agreement between two different measures of QOL, as well as comparisons between those who did and did not receive caregiving services. These included:

*Response shift and quality of life correlations.* The entire qualitative dataset for SCI participants (N=40) was coded for the components of Schwartz, et al.’s<sup>3</sup> Response Shift (RS) model, resulting in a matrix used for qualitative analysis. Narrative data were then quantified using a scoring system, rating participants’ RS on a scale from 0 (no RS) to 2 (full RS), with 1 showing Some RS. Analysis of Variance was used to look at differences in both self-reported QOL scores (1-10) during semi-structured interviews and from the PROMIS Global Quality of Life as a function of

RS. Overall, QOL scores varied significantly as a function of RS ( $p=.013$ ) as did PROMIS Global Physical Health Scores ( $p=.009$ ), while PROMIS Global Mental Health Scores did not ( $p=.219$ ) suggesting that in this sample, the concept QOL is likely to be reflective of adaptation towards physical health issues (RS). Post-hoc analyses of the QOL scores showed that those in the Some RS category had substantially lower scores than did those in the Full RS category (8.3 vs. 6.5;  $p=.004$ ). Post-hoc analyses of PROMIS Global Physical Health Scores showed that those with Full RS had significantly higher scores (8.3) than did those with either the No RS (37.3;  $p=.017$ ) or Some RS (39.9;  $p=.008$ ). Taken together, these compared scores confirms the premise of the Schwartz model, in that RS correlates with perceived QOL. Further, this correlation validates our assessments of participants' RS; our qualitative analysis of RS benefits from clear statistical associations, validating our RS categories (as discussed in Data Analysis for Year 3).

*Rates of agreement between two different measures of QOL.* The concept of QOL was assessed in multiple ways. Two methods were compared: single scores (ratings 1-10) collected during semi-structured interviews and the PROMIS Global Quality of Life measure used two weeks later. Mean QOL scores from the interviews were 7.3 (SD= 1.9). Mean scores on the PROMIS Global Mental and Physical Health scores were 50.5 and 42.0 (SDs = 8.7 and 6.5). Pearson correlations were conducted to assess the relationship between responses to these two measures. While the correlation between QOL ratings and PROMIS Global Physical Health scores were nominal ( $r=.20$ ;  $p=.210$ ) the correlation of QOL ratings and PROMIS Global Mental Health scores were quite substantial ( $r=.70$ ;  $p<.0005$ ). Taken together, these comparisons suggest the measurement of QOL during semi-structured interviews was comparable to those in the standardized measures, reaffirming the findings in each. It is worth noting that the QOL scores from interviews were a one-item question, followed by a narrative explanation of the number chosen. The correlations suggest the value of collecting numerical self-reported data during semi-structured interviews, allowing for statistical analyses, followed by paired narrative data to facilitate thematic analyses.

*Comparison of SCI participants receiving and not receiving caregiver services.* Those who received caregiver services reported significantly more anxiety, as measured by the PROMIS Anxiety Scale (48.3 vs. 41.5;  $p=.05$ ). QOL ratings from the semi-structured interviews were essentially the same. While there were no significant differences in complications, several trends were observed, with those receiving caregiver services being less likely to report constipation (41.9% vs. 66.7%), more likely to report hemorrhoids (54.8% vs. 33.3%) and more likely to report 4 or 5 complication (65.5% vs. 44.4%). People receiving caregiver services were more likely to be married (54.8% vs. 11.1%;  $p=.02$ ) and more likely to have tetraplegia (51.6% vs. 11.1%;  $p=.03$ ). This last finding may explain why they tended to have 4 or 5 complications, since having tetraplegia puts one at greater risk. The lack of more statistically significant findings may be due to the fact that only 9 participants did not receive caregiver services.

*Findings related to Aims 1 and 2.* In relation to Aim 1 (risk factors), personal factors such as level of impairment, age, time since injury, access to resources (i.e. caregivers, supplies for catheterization) and social opportunities appeared related to one manages his/her bowel and bladder complications. Methods of management were also associated with complications and narratives also described limited access to clean catheters are related to UTIs. Access to clean catheters were reported as critical to avoiding recurrent UTIs. Those using IC had lower bladder complications. Further, there are some early findings suggesting different rates of UTIs in those who use self-catheterization and those who received assistance. Recurrent UTIs may be more likely in those with caregivers, risking the introduction of additional bacteria. In relation to both Aims 1 and 2, participants' ability to adapt and make behavioral changes resulted in positive responses (RS) to complications and greater QOL. Based on the BBTI and related quantitative analyses, higher QOL was associated with fewer complications. Time since injury was

significantly associated with QOL with those with less than one year since injury reporting lower QOL ( $p<.013$ ). Looking at our qualitative data on response shift and examining differences between civilians and veterans, findings showed that more veterans than civilians with SCI showed little or no indication of making behavioral changes indicative of positive response shifts. On the other hand, more veterans than civilians showed a higher number of responses indicative of full response shift. It is possible that veterans as a group exhibit more diverse characteristics than civilians. They either made changes associated with positive outcomes or they did not. This polarization of findings seems to also speak of veterans' tendencies to seek more drastic solutions for their problems related to bowel and bladder, such as incontinence and UTIs. While these findings are difficult to confirm due to the inherent limitations of this project (i.e. small samples, scope of the investigation, different age cohorts) they deserve further exploration in future studies designed to focus on the process by which one appraises complications, adapts and makes decisions that positively impact their QOL after SCI.

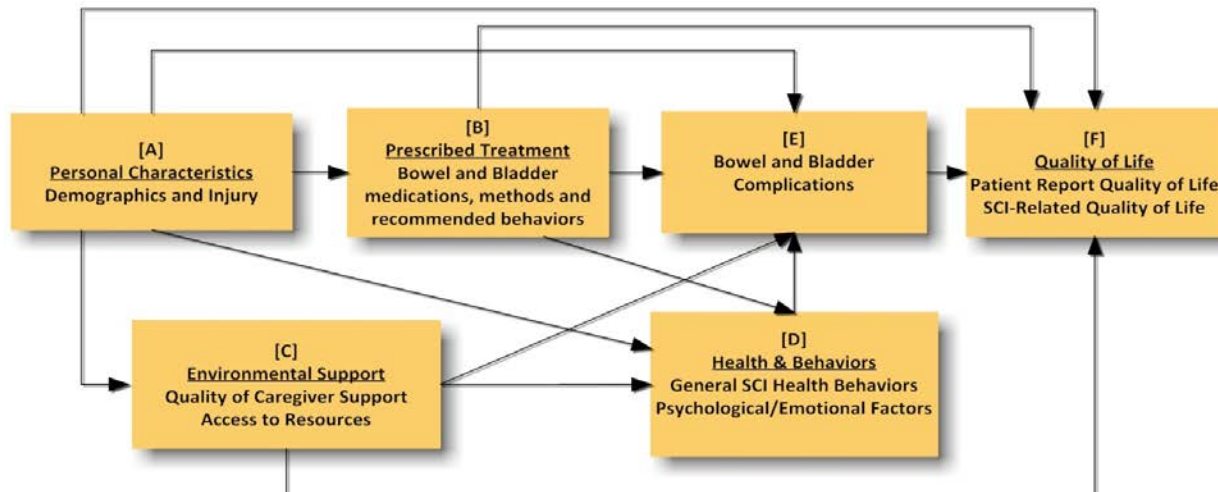
*Focus group findings.* Focus group transcripts were read and assessed for general findings. SCI focus groups resulted in three dominate themes: loss of daily spontaneity, lack of physicians in the community knowledgeable about SCI patient needs, and individual definitions of QOL, with variations of QOL on a daily basis. Managing bladder and bowel becomes a daily “balancing act,” requiring daily diligence and increasing knowledge towards more-successful management strategies. The caregiving focus group focused heavily on the stress of caregiving, including constant vigilance as caregivers and lack of free time. QOL suffered as a result of poor bladder and bowel management and changing spousal roles following SCI. Overall, these themes tended to conform to trends in the individual interview data, while providing clearer focus on the most salient issues. As we continue dissemination, focus group findings will be more-carefully investigated both alone and as supporting data for larger analyses of the entire dataset.

### Other Achievements

The PI chaired a workshop and presented data on quality of life measurement for spinal cord injury at the 55<sup>th</sup> Annual Meeting of ISCoS cited above. The presentation entitled “Towards a Common Standard for Quality of Life Measurement in SCI Research and Clinical Practice” focused on the use of the international datasets for QOL measurement but used examples from this projects illustrating narrative text about QOL by persons with SCI. Further, during this year, a manuscript exploring risk factors associated with neurogenic bladder and bowel complications after SCI was published, informed in part by work done in this project.<sup>8</sup>

## KEY RESEARCH ACCOMPLISHMENTS

Major research accomplishments are reflected in Table 1. These are discussed here in relation to the project conceptual model (Figure 1) describing factors associated with bladder and bowel complications and QOL. These factors are (a) personal characteristics including demographics and neurological impairment; (b) treatments or methods of management for bowel and bladder; (c) environmental resources including access to supplies and caregivers; (d) behavioral factors such as psychosocial adaptation, response shift and health behaviors (e) complications; (d) bowel and bladder complications; and (f) QOL. See Figure 1 below.



**Figure1. Factors Associated with Bladder and Bowel Complications and QOL after SCI**

This model, based on the International Classification of Functioning, Disability and Health (ICF), posits relationships among these factors, describing the influence of these on complications and QOL outcomes. Table 1 summarizes our findings in relation to this model using a mixed method approach which emphasizes qualitative methods of inquiry to best capture details in these relationships, aided by quantitative analyses.

**Table 1. Key Research Accomplishments by Aims and Factor Clusters (A-E)**

Project Aims	Conceptual Factors	Findings and Accomplishments
Aim 1: Risk factors to Complications	A – Personal Factors	Time since injury (TSI) was associated with QOL; satisfaction with social roles; and neurological classification.
	B – Methods of Management	Most frequent methods of management were intermittent catheterization (IC) and digital stimulation and evacuation.
	C – Environmental Resources	Access to clean catheters to avoid recurrent UTIs was a frequent theme during interviews. Caregiver access did not influence complications/QOL.

	D – Behaviors	Response Shift (RS) proved to be a valid model for behavioral adaptation in relation to complications and QOL. Behavior driven changes were associated with higher QOL.
	E – Complications	Those using IC reported fewer bladder complications. UTIs were more frequent in those with tetraplegia. Civilians and veterans did not differ in terms of complications.
Aim 2: Complications to QOL	E	Most frequent complications included UTIs and hemorrhoids.
	A, B, C	QOL was less related to demographics, management methods and resources.
	D	QOL was strongly associated with RS behaviors and mental health while RS was related to perceptions of physical health.
	F	QOL was associated with satisfaction with social roles in spite of complications.

### **Milestones and Major Achievements**

Since its inception, the project accomplished a number of milestones related to the establishment of a common infrastructure for future research collaborations between military and non-military health facilities, data sharing mechanisms, and dissemination products. These are depicted in Table 2.

**Table 2. Key Accomplishments and Milestones by Project Year**

<b>Project Years</b>	<b>Major Achievements</b>	<b>Outcomes/Products</b>
Year 1: 2012-13	Established collaborative infrastructure between UMHS and AA Veteran Medical Center	<ul style="list-style-type: none"> <li>• Procedures manual</li> <li>• Interview Guides</li> </ul>
Year 2: 2013-14	Advisory Council Meeting Revised Coding Scheme	<ul style="list-style-type: none"> <li>• Coding Manual</li> <li>• MPVA presentation</li> <li>• 2 abstracts and one ISCoS presentations</li> </ul>
Year 3: 2014-15	Recruitment completed Coding for Participants Completed; QOL,	<ul style="list-style-type: none"> <li>• Nevedal et al. publication</li> <li>• ISOQOL presentation and abstract</li> </ul>

	complications and RS matrices developed	<ul style="list-style-type: none"> <li>• ICORD and Canadian PM&amp;R presentations</li> <li>• 2 proposals submitted</li> </ul>
Year 4: 2015-16	Complications, QOL, RS and Caregivers data analysis	<ul style="list-style-type: none"> <li>• Caregivers report</li> <li>• Focus groups reports</li> <li>• PVA abstract and presentation</li> <li>• ISCoS abstract and presentation</li> <li>• ACRM abstracts and presentations (2)</li> <li>• SCIRP Progress Review</li> <li>• ANZSCoS presentation and abstract</li> <li>• 3 proposals submitted</li> </ul>

Presentations and abstracts are detailed in Reportable Outcomes. In summary, these milestones reflect infrastructure required to conduct the project, data analyses leading to presentations and one publication so far, with three others in preparation. One proposal was submitted on to the CDMRP-SCIR qualitative program to focus on the decision-making process leading to solutions to bowel and bladder complication (pending) and two to the Craig Nielsen Foundation; one to develop a measure of caregiving (funded) and another to examine the validation of the QOL basic dataset from the SCI International Datasets (funded). If valid, this will represent an easy to use and quick measure of QOL that can be included as part of SCI patients' electronic medical records to be used during clinical examinations. The funded caregiver project will develop a more comprehensive measure of the quality of the relationship between people with SCI and their caregivers than the QCM that was used in this study. Researchers are also examining this dataset in relation to data on complications from other datasets.

## **REPORTABLE OUTCOMES**

Project investigators have produced a number of dissemination products to date. Many have focused on the experiences of neurogenic bladder and bowel, including investigations that differentiate between veterans and civilians with SCI. A variety of presentations have focused on the response shift model to explain how participants adapted to their injuries and complications around bladder and bowel management. Finally, a number of grant applications were conceived, developed, and submitted stemming directly from work done through this award. Dissemination projects are ongoing, with an emphasis on manuscript publication over the next year, now that data analyses are more complete.

### **Publications**

Nevedal A, Kratz A, and Tate D. (2016) "Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel." *Disability and Rehabilitation*: 38(6):573-581.

Tate DG, Forchheimer M, Rodriguez G, Chiodo A, Cameron AP, Meade M, and Krassioukov A (2016) "Risk Factors Associated with Neurogenic Bowel Complications and Dysfunction in Spinal Cord Injury." *Archives of Physical Medicine & Rehabilitation*. 97(10):1679–1686.

### **Presentations**

#### **Platform presentations**

Tate D, Forchheimer M, Rodriguez G, Chiodo A. (2015, May). Application of quality of life measures in clinical settings: Focusing on bowel and bladder care for spinal cord injury. Platform presentation at the *Canadian Association of Physical Medicine and Rehabilitation. Annual Scientific Meeting*, Vancouver, Canada.

Tate D. (2015, May). Patient reported outcomes related to neurogenic bowel and bladder after SCI: "My bowels have a mind of their own". Platform presentation at the *3<sup>rd</sup> International Autonomic Symposium: Dysfunctions of the Autonomic Nervous System*. (ICORD), Vancouver, Canada.

Tate D. (2015, May). Changes in medical issues: Criterion validity and responsiveness to change for the bowel and bladder management item banks. Platform presentation at *Joint Conference of the American Spinal Cord Injury Association and the International Spinal Cord Society*. Montreal, Canada.

Tate D, Rohn E, Duggan C, Madrid R, Forchheimer M, Zafiroff E. (2015, October). Response shift and perceptions of quality of life following neurogenic bladder and bowel in persons with spinal cord injury. Platform presentation at the *22<sup>nd</sup> Annual Conference of the International Society for Quality of Life Research (ISOQOL)*, Vancouver, British Columbia, Canada.

Rohn E, Tate D, Zafiroff E, Forchheimer M, Duggan C, DiPonio L. (2016, August). Response shift in veterans and civilians with neurogenic bladder and bowel following spinal cord injury. Platform presentation at the *Paralyzed Veterans of American Annual Summit and Expo*, Orlando, FL.



Forchheimer M. (2016, August). Patient-Provider Relationship: Associations with Clinician Type, Demographics and Other Factors. Platform presentation at the *Paralyzed Veterans of American Annual Summit and Expo*, Orlando, FL.

Tate D, Charlifue S, Post M, New P. (2016, September). Towards a Common Standard for Quality of Life Measurement in Spinal Cord Injury Research and Clinical Practice. Workshop Chair and presenter at the *55<sup>th</sup> Annual Scientific Meeting of the International Spinal Cord Injury Society (ISCoS)*, Vienna, Austria.

Tate D. (2016, October). Psychosocial and behavioral factors associated with bowel and bladder management after SCI. *CDMRP In-progress Review, Spinal Cord Injury Program*, Fort Detrick, MD.

Tate D. (2016, November). A theory for everything: From coping to shifting: A tribute to Paul Kennedy. Key note presentation at the *2016 Annual Conference of the Australian & New Zealand Spinal Cord Society (ANZSCoS)*, Adelaide, Australia. Published abstract, p. 28

#### Poster presentations

Tate D, Forchheimer M, Chiodo A, Rodriguez G, Cameron A. (2013, October). The effects of bowel and bladder dysfunction on quality of life after SCI. Poster presentation at the *52<sup>nd</sup> Annual Scientific Meeting of the International Spinal Cord Society (ISCoS)*, Istanbul, Turkey.

Tate D, Forchheimer M, Chiodo A, Rodriguez G, Cameron A, Hartwig R, Pines C. (2013, October). Development of interview forms for the international spinal cord injury datasets for bladder and bowel. Poster presentation at the *52<sup>nd</sup> Annual Scientific Meeting of the International Spinal Cord Society (ISCoS)*, Istanbul, Turkey.

Tate D, Forchheimer M, Rodriguez G, Chiodo, A, Cameron A, Kalpakjian C, Faleiros F, Hartwig R, Pine C, Schiller S. (2015, May). Development of a measure to assess bowel and bladder dysfunction. Poster presentation at the *Joint Conference of the American Spinal Cord Injury Association and the International Spinal Cord Society*. Montreal, Canada.

Tate D, Forchheimer M, Greve J, Castineira C, Oyakawa A, Pines C, Faleiros F. (2015, May). Cross cultural comparisons using a translated version of the international spinal cord injury quality of life data set: Preliminary findings. Poster presentation at the *Joint Conference of the American Spinal Cord Injury Association and the International Spinal Cord Society*. Montreal, Canada.

Forchheimer M, Tate D. (2015, May). Patient-Provider Alliance: Relationships with Clinician Type, Life Satisfaction, Health Maintenance and Bowel and Bladder Management. Poster presentation at the *Joint Conference of the American Spinal Cord Injury Association and the International Spinal Cord Society*. Montreal, Canada.

Tate D, Rohn E, Zafiroff E, Madrid R, Nevedal A. (2015, June). Response shift and perceptions of quality of life in newly versus long-term-injured persons with spinal cord injury. Poster presentation at the *9<sup>th</sup> International Society of Physical and Rehabilitation Medicine World Congress (ISPRM)*, Berlin, Germany.

Tate D, Rohn E, Forchheimer M, DiPonio L, Rodriguez G. (2016, September). Complications with neurogenic bladder and bowel among veterans and civilians with spinal cord injury. Poster presentation at the 55<sup>th</sup> Annual Scientific Meeting of the International Spinal Cord Injury Society (ISCOs), Vienna, Austria.

Rohn E, Tate D, Forchheimer M, Zafiroff E, Duggan C. (2016, October). Utilizing a response shift model to explain quality of life following spinal cord injury. Poster presentation at the 93<sup>rd</sup> Annual Meeting of the American Congress of Rehabilitation Medicine (ACRM) Chicago, IL.

Tate D, Rohn E, Forchheimer M, Duggan C, DiPonio L, Rodriguez G. (2016, October). Complications to neurogenic bladder and bowel after spinal cord injury: the military veteran's perspective. Poster presentation at the 93<sup>rd</sup> Annual Meeting of the American Congress of Rehabilitation Medicine (ACRM), Chicago, IL.

### **Grants Written Based on Award**

"Validation of the international SCI Quality of Life basic dataset (SCI-QOLBDS): Cross-cultural comparisons and clinical outcomes". (2016). Craig H. Neilsen Foundation. PI: Tate D. AWARDED

"Developing a patient-centered measure of caregiver relationships". (2016). Craig H. Neilsen Foundation. PI: Forchheimer, M. AWARDED

"Neurogenic bowel and bladder management after spinal cord injury: examining factors involved in successful decision-making processes". (2016). Defense Congressionally Directed Medical Research Programs, Qualitative Research Award. PI: Tate D. SUBMITTED

"Patients, providers and caregivers in the context of chronic pain management for veterans and non-veterans with spinal cord injury". (2014). Defense Congressionally Directed Medical Research Programs. Qualitative Research Award. PI: Tate, D. NOT AWARDED

"Dynamics of patient-provider collaboration and chronic pain management for patients with spinal cord injury". (2014). Craig H. Neilsen Foundation. PI: Tate, D. NOT AWARDED

## **CONCLUSION**

This study attempted to understand the many factors related to neurogenic bladder and bowel following SCI, including personal characteristics, methods of management, medical and psychosocial complications and environmental support, as well as the influences of these factors on QOL outcomes. The use of a qualitative methodology supplemented by quantitative data allowed us to examine the conceptual model initially proposed for the project demonstrating associations among various factors and their influences on QOL. The two aims focused on the identification of risk factors associated with bladder and bowel complications and determining the relationship of these complications to QOL.

The literature reviewed earlier provided some indication of potential risk factors (i.e. age, gender, TSI, neurological impairment, and methods of management) associated with such complications. While this study was limited in providing a clear picture about the complex interactions among these factors, its quantitative findings provided support for both TSI and level of impairment being major determinants of complications. The direction of these findings was not surprising, confirming findings in the literature about severity of impairment and duration of injury being related to an increased number of complications. From a qualitative perspective, we were able to capture expressive information about beliefs, values, feelings and motivations of participants facing these complications over time and their potential impact on QOL. The ability to further contextualize this information highlighted the important role of adaptive positive behaviors in addressing problems, seeking solutions and making decisions to solve them versus experiencing feelings of resignation and despair or accommodation by recalibrating their values and belief systems.

The fact that more veterans than civilians seem to make decisions about changing their methods of bladder or bowel management, often resorting to more surgical and less recommended approaches, was intriguing and warrants further exploration. A combination of factors may have contributed to these results, such as the influence of military training on one's inclination to take action and solve problems. The greater access to resources through that veterans have through the VA for having these procedures may have also been a factor as might veterans sense of entitlement and differences in physicians' attitudes.

Our findings emphasize the critical role of behavioral factors in influencing QOL and in addressing neurogenic bladder and bowel complications. The salience of many such behaviors and appraisals were reinforced in the SCI focus groups. Further, the RS model provided us with a robust conceptual model to examine the role of these behavioral factors, suggesting the importance of targeting behavioral interventions to address complications especially among those at risk (e.g. those aging with SCI and those with tetraplegia). Second, our findings highlight the importance of social roles (i.e. having a professional identity, serving as a role model to others, being able to give back to the community in some meaningful way) and social support provided by family members, spouses and children. Not surprisingly QOL ratings varied as a function RS and global perceptions of physical health, suggesting that among study participants, the ability to adapt to changes in health directly influences QOL. Thirdly, there are implications for healthcare delivery and the implementation of complex interventions. Assessing RS for patients could assist professionals in assessing readiness to change, psychological strength in enduring new or challenging interventions that may improve QOL once complete, and may prove predictive of adherence.

Our data about caregivers suggests the importance of educational interventions to facilitate communication among caregivers and recipients of care and to address issues of burden of care

and stress among caregivers. Early focus group findings were very clear about the salience of stress and the negative impact on QOL for caregivers who do not receive enough down time from their caregiving tasks. Preliminary analysis of caregiving across both SCI and caregiver interviews revealed telling differences in the behavioral interactions between caregivers and care recipients. Early findings suggest differences in appraisals between caregivers (seeing their work as paramount and being consumed with bladder and bowel management details) and care recipients (taking caregiving for granted and being less concerned with management details). Those with SCI tended to minimize the role caregivers played in their care, while caregivers become consumed with minutia of care. We will continue exploring these differences. Lastly, our findings about QOL were validated using a triangulation approach combining quantitative and qualitative data, suggesting the importance of multiple measures, suggesting benefits of each tool.

Limitations of this study included the lack of equivalent samples from civilian and veterans' cohorts as data on recent injuries was only collected among civilians. The lack of access to recently injured soldiers with SCI limited our ability to examine issues of behavioral adaptation to changes in health due to neurogenic bladder and bowel within a different context of factors. Lastly, the relatively lack of diversity among caregivers during the focus group discussions may have biased our results towards issues of family caregiving.

Future work will include a heavy emphasis on dissemination. A number of manuscripts are in various stages of preparation: two manuscripts on response shift, a case study paper on resilience over time, a survey of complications and their impact on daily life, an examination of different appraisals and behaviors around bowel and bladder management comparing caregivers and SCI participants, and a methodology paper on our work triangulating between mixed methods data sources, particularly around QOL. More manuscripts are being planned. New grants are also being considered. Moving forward, additional research will target decision-making processes for changes in bladder and bowel management, behavioral factors in caregiving that help mitigate complications, examining differences between self- and assisted-catheterization in rates of UTIs, and the possible development of a measure of RS for clinical use in those with SCI.

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7. Nevedal A, Kratz AL, Tate DG. Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel. *Disability and rehabilitation*. 2016;38(6):573-581.
8. Tate DG, Forchheimer M, Rodriguez G, et al. Risk factors associated with neurogenic bowel complications and dysfunction in spinal cord injury. *Archives of physical medicine and rehabilitation*. 2016;97(10):1679-1686.

## **APPENDICES**

Appendices accompanying this final report include:

- Original Statement of Work
- Personnel Report
- Operations Manual (including interview data collection protocols/measures)
- SCI Participant Coding Scheme
- SCI Participant Coding Manual
- Caregiver Participant Coding Scheme
- Caregiver Participant Coding Manual
- SCI Focus Group Protocol
- Caregiver Focus Group Protocol
- Caregiver Interviews Report
- Three (3) Focus Group Reports

## **Statement of Work**

The primary goal of the statement of work is to describe an operation plan which will ensure that project activities are accomplished on time, within budget as proposed, and according to high quality standards, precision and accuracy. We outline below the six major areas of project activities to be accomplished during this three year study.

1. **Administrative tasks** include those being performed at different sites as well as project start-up and recruitment of personnel; coordination with work sites; submission of IRBs; orientation of advisory or steering committee members; maintaining relationships with Department of Defense CDMRP and SCI program representatives, grant administration and coordinating and overseeing consultants' involvement across sites. Three sites are involved: 1) University of Michigan/Dept. of Physical Medicine and Rehabilitation (lead site/PI: Tate); 2) VA Ann Arbor Healthcare System (site PI: Diponio); and Michigan Paralyzed Veterans of America (site contact: Michael Harris). This third site serves the function of recruitment, dissemination and guidance to project activities. Research will be conducted primarily by the first two sites listed. (Months 1-36)
  - 1a. Project start-up activities (Months 1-6)
    - Recruitment of Research Associate
    - Award notification of sites and meetings to coordinate plan of operations
    - Grant administration accounts, faculty and staff appointments
    - U-M site (Tate, Kalpakjian, Forchheimer, Cameron, Rodriguez)
    - VA site (Diponio, Roth)
    - Meeting with Steering Committee (Harris, Loyer, Werner, Chiodo)
    - Supplies and equipment purchases
  - 1b. IRB and other regulatory approvals required by U-M, VA and CDMRP (Months 2-6)
    - U-M and VA IRB approval
    - Certificate of environmental compliance
    - Safety program documents
  - 1c. Submission of research reports to the Department of Defense (Months 11, 24 and 36)
  - 1d. Consultants agreements/scope of work and timelines confirmed (Months 1-3)
  - 1e. Establishment of DSMB (Data Sharing and Management Board) (Months 3-6)
  - 1f. Contract with transcription services (Months 3-4)
  - 1g. Payment of subject fees for participation (Months 6-30)
2. **Research design tasks** include development and refinement of conceptual steps for both the qualitative and quantitative aspects of the study; refinement of the semi-structured individual and focus group interviews for SCI participants and caregivers; review of measures; refinement of diary format and summary forms; develop database and data sharing plan. (Months 1-10)
  - 2a. Development, refinement and review of interviews and study measures (1-3)
  - 2b. Pilot of measures and interviews with SCI participants and caregivers (Months 3-4)
  - 2c. Refinement of Bladder and Bowel Diary format and reporting forms (Months 3-5)
  - 2d. Development of databases in Word, Excel, SPSS and NVivo (Months 5-10)
  - 2e. Review of plans for data sharing and dissemination of products (Months 7-10)

3. **Recruitment related tasks** include development of a plan for recruitment to include all sites with special attention given to the VA and MPVA. The U-M SCIMS database will serve as another source of recruitment as will our SCI Registry and community-based agencies. (Months 5-30)
  - 3a. Send letters of invitation, phone contacts, informed consents and conduct eligibility verification with participants; scheduling interviews and focus groups (Months 6-25)
  - 3b. Organize interview schedules and focus group activities with the sites (Months 6-25)
4. **Data collection and data processing tasks** include conducting interviews with the 50 participants (persons with SCI and caregivers); conducting focus groups; processing qualitative and quantitative data and data entry (Months 6-33)
  - 4a. Train interviewers, conduct individual interviews, administer measures (Months 6-30)
  - 4b. Have SCI participants complete 2-week Bowel and Bladder Diaries and Summaries (Months 6-31)
    - 4c. Enter data based on subject diaries into SPSS database (Months 7-32)
    - 4c. Conduct two focus group interviews, with SCI and caregiver groups (Months 25-30)
    - 4d. Mail audiofiles to the transcription services (Months 9-31)
  - 4e. Review interview transcripts in Word database, clean data, enter narratives into the NVivo database, code qualitative interviews, conduct inter-rater reliability for coding; score all quantitative measures and enter these into SPSS database (Months 10-33)
  - 4f. Have focus group audiofiles transcribed, enter narratives into NVivo database and code interviews (Months 22-33)
5. **Data analysis and evaluation tasks** include mixed method analysis and triangulation of data. Includes evaluation activities related to the conduct of the investigation itself (Months 11-35)
  - 5a. Prepare basic statistics to describe samples and their scores, perform statistical analysis and qualitative analysis of transcripts for themes and patterns (Months 11-34)
  - 5b. Conduct triangulation of qualitative and quantitative data sets (Months 15-34)
  - 5c. Review data regularly to evaluate coding schemes, discuss patterns emerging, and findings from the quantitative analysis. (Months 13-33)
  - 5d. Review focus group data and integrate it with other qualitative data (Months 20-33)
  - 5e. Analyze data from the Bowel and Bladder Diaries, including conduct of linear mixed models. (Months 24-34)
  - 5f. Conduct regular meetings to discuss data interpretation and evaluation (Months 11-35)
6. **Dissemination and data sharing tasks** include discussions with focus groups at U-M, VA and MPVA, presentations at the AACIL and national meetings, website links to project activities, products and findings. We will use the existing U-M SCIMS website with links to the VA and MPVA sites to distribute this information. (Months 10-36)
  - 6.1 Appointment of a DSMB and development of a data sharing plan (Months 5-10)
    - 6a. Development and dissemination of findings in lay language to persons with SCI, their families and caregivers through a second presentation at the AACIL, consumer brochures and fact sheets. These will be distributed through websites, presentations and meetings. (Months 25-35)
    - 6b. Presentations to clinicians and researchers at professional meetings about the scope and importance of the project findings and recommendations. (Months 10-36)
    - 6c. Presentations at DoD and CDMRP sponsored meetings (Months 11-36)
    - 6d. Preparation of final report and manuscripts (Months 15-36)



### Timeline for Completion of Major Research Activities

	Year 1				Year 2				Year 3			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
<b>Administration</b>												
Project Start-up	X	X										
IRBs and DSMB	X	X	X									
Submission of Reports				X				X				X
<b>Research Design</b>												
Refinement of Interviews & Measures	X	X										
Development of Databases		X	X	X								
<b>Recruitment</b>		X	X	X	X	X	X	X	X			
<b>Data Collection &amp; Processing</b>												
Conduct Interviews and Focus Groups, Complete Measures and Diaries		X	X	X	X	X	X	X	X	X		
Code and Enter Data			X	X	X	X	X	X	X	X	X	
<b>Data Analysis</b>												
Analyze Qualitative Data				X	X	X	X	X	X	X	X	X
Analyze Quantitative Data				X	X	X	X	X	X	X	X	X
Analyze Diary Data								X	X	X	X	X
Triangulate Qualitative and Quantitative Data						X	X	X	X	X	X	X
<b>Dissemination</b>												
Disseminate Findings to Lay Audiences				X			X		X	X	X	X
Disseminate to Clinicians & Researchers				X	X	X	X	X	X	X	X	X

## Personnel Report

<b>Year 1 (10/1/2012–9/31/2013)</b>		
<b>Name</b>	<b>Sum of Hours</b>	<b>Effort</b>
Forchheimer, Martin	60.80	4.99%
Kalpakjian, Claire Z	43.60	3.58%
Kratz, Anna L	52.40	4.30%
Pines, Constance A	34.00	2.79%
Rohn, Edward J	608.00	49.92%
Tate, Denise G	126.40	10.38%

<b>Year 2 (10/1/2013–9/31/2014)</b>		
<b>Name</b>	<b>Sum of Hours</b>	<b>Effort</b>
Forchheimer, Martin	104.40	5.00%
Kalpakjian, Claire Z	0.00	0.00%
Kratz, Anna L	52.00	2.49%
Madrid, Roxanne	38.72	1.85%
Pines, Constance	39.90	1.91%
Rohn, Edward J	2,088.00	100.00%
Steffens, Sarah	128.20	6.14%
Tate, Denise G	313.20	15.00%

<b>Year 3 (10/1/2014–9/31/2015)</b>		
<b>Name</b>	<b>Sum of Hours</b>	<b>Effort</b>
Forchheimer, Martin	173.60	8.31%
Madrid, Roxanne	368.67	17.66%
Pines, Constance	57.50	2.75%
Rohn, Edward	2,088.00	100.00%
Steffens, Sarah	61.30	2.94%
Tate, Denise G	313.20	15.00%
Zafiroff, Emily	484.00	23.18%

<b>Year 4 (10/1/2015–9/30/2016) plus two additional months (10/1/16–11/30/16)</b>		
<b>Name</b>	<b>Sum of Hours</b>	<b>Effort</b>
Forchheimer, Martin	628.46	30.10%
Madrid, Roxanne	68.14	3.26%
Pines, Constance	5.50	0.26%
Rohn, Edward	924.00	44.25%
Steffens, Sarah	6.90	0.33%
Tate, Denise G	577.60	27.66%
Zafiroff, Emily	160.00	7.66%

# **DOD RESEARCH PROJECT**

*Psychosocial and Behavioral Factors  
Associated with Bowel and Bladder Management after SCI*

## **DATA COLLECTION PROCEDURES MANUAL**

Prepared by:  
Edward J. Rohn, Study Coordinator

Updated:  
**February 4, 2014**

## **CONTENTS**

1. Recruitment & Screening Procedures
  - a. Step-by-step guide
  - b. UM COMBINED Oral recruitment script (SCI/Caregiver uses one script)
  - c. UM SCI screening form
  - d. UM Caregiver screening form
  - e. UM SCI Recruitment flyer
  - f. UM Caregivers Recruitment flyer
  - g. VA SCI Oral recruitment script
  - h. VA Caregiver Oral recruitment script
  - i. VA SCI screening form
  - j. VA Caregiver screening form
  - k. VA Recruitment flyer
  - l. Interviewer roles chart
2. Consent & Interview Procedures
  - a. Step-by-step guide
  - b. UM SCI consent form
  - c. UM Caregivers consent form
  - d. UM Obtaining informed consent checklist (MUST USE and FILE)
  - e. UM Obtaining informed consent script
  - f. VA SCI consent form
  - g. VA Caregiver consent form
  - h. VA Obtaining informed consent checklist (MUST USE and FILE)
  - i. FOCUS GROUP informed consent form
  - j. FOCUS GROUP obtaining informed consent script
  - k. SCI interview guide
  - l. SCI quantitative measures LESS THAN ONE YEAR
  - m. SCI quantitative measures MORE THAN ONE YEAR
  - n. SCI Questionnaire response cards
  - o. Appointment reminder form
  - p. Caregivers interview guide
  - q. Caregivers demographics form
  - r. Interview receipt
3. Post Interview & Data Management Procedures
  - a. Step-by-step guide

## 1. RECRUITMENT & SCREENING PROCEDURES

1. Potential SCI subjects are identified in one of three main ways:
  - a. Databases (registries and physician patient lists)
  - b. Advertising (flyers, websites, and newsletters)
  - c. Referrals (direct physician referrals, other participants, allied sources – Connie)
2. Potential subjects are sent recruitment letters by the relevant registry's manager (Rachel Hartwig @ UM and Amanda Raine @ VA) – each site has own IRB-determined opt-out window.
  - a. UM potential subjects have a two-week window to opt-out.
  - b. VA potential subjects have a three-week window to opt-out.
3. Once the allotted time windows have expired, the contact information of those that did not opt out will be forwarded from the relevant registry manager to the DoD study coordinator (Rohn).
4. Study coordinator (Rohn) will assign unique Subject ID#s to each potential subject, following in sequential order from the last known Subject ID#.
  - a. UM SCI subjects will be labeled as – UM-0XX (for example, UM-001, UM-025, etc).
  - b. VA SCI subjects will be labeled as – VA-0XX (for example, VA-001, VA-032, etc).
  - c. UM Caregivers will be labeled as – UM-1XX (for example, UM-101, UM-109, etc.)
  - d. VA Caregivers will be labeled as – VA-1XX (for example, VA-101, VA-109, etc.)
5. Study coordinator (Rohn) will call potential subjects to complete the relevant oral recruitment script and relevant screening form. Will recruit additional help in this as needed.
  - a. There are specific oral recruitment scripts and screening forms for each site (UM, VA)
  - b. Also, different oral recruitment scripts and screening forms for each arm (SCI, Caregiver)
6. Enrollment
  - a. If subject passes the screening and agrees, they can considered to be “enrolled”.
  - b. Those that do not pass screening, but want to participate, should be brought the PI (Tate, DiPonio) for final decision on enrollment.
7. Study coordinator (Rohn) will assign one or two interviewers to each subject, depending on the subject, project roles, and current workload. See attached Interview roles chart for details:

8. Study coordinator will provide interviewers with Subject ID#s. These can be used to acquire contact information, medical data relevant to injury (if applicable), and the findings of the screening procedure.
  - a. For UM subjects, REDCap will provide all the relevant contact information.
  - b. In cases where someone does not have access to REDCap, the study coordinator (Rohn) can provide this information in a secure correspondence (telephone or direct handoff).
  - c. For VA subjects, all contact information will be stored on the secure VA server in an Excel spreadsheet.
9. See attached forms for your convenience. Forms are also stored on the shared drive (folder labeled "DoD Project 2012")

## ORAL RECRUITMENT SCRIPT

## HUM68800

---

Hello, my name is XXX and I am calling from the University of Michigan Department of Physical Medicine and Rehabilitation. I want to tell you about a new study we are doing to see if you would be interested in joining. Would that be OK?

IF NO, thank them for their participation and hang up.

IF YES, proceed to the following:

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. The study is asking persons with SCI (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. Would you be interested in joining this study?

IF NO, thank them for taking the time to hear about it and hang up.

IF YES, proceed to the following:

**FOR EVERYONE:** The study has two parts. The first is a one-on-one interview, which can be done over the phone or in person, for example at your house or at the clinic – talking in depth about issues such as the kinds of problems you experience with bowel and bladder and how these affect your independence, coping with problems, or how taking care of bowel and bladder functions affects intimate and family relationships. The interview will take 60 – 90 minutes to do.

**FOR SCI ONLY:** You will also complete a series of questionnaires about your mood, the quality of care you get, and your bowel and bladder program and any specific problems you may have. That should take another 60 – 80 minutes.

**FOR EVERYONE:** Next, if you choose to do so, you may also participate in a focus group, on a different day, which will take 60 - 90 minutes to complete; there will be a focus group for people with spinal cord injury and a separate one for caregivers. The focus groups will be held in Ann Arbor in a place that is accessible and easily reached by the highway or other main roads.

Does this sound like something you would be interested in doing?

IF NO, thank them and hang up.

IF YES, proceed to the following.

If you have time, I have a few more questions for you. These are more specific and will help me confirm your eligibility for the study. Would it be OK for me to ask you those questions now?

IF YES, proceed to the SCI SUBJECT SCREENING FORM or the CAREGIVER SUBJECT SCREENING FORM, as appropriate.

IF NO, proceed to the following.

Thank you for agreeing to join this study! When is a good time to contact you so we can go through the questions in order to confirm your eligibility? Is this the best number to use to contact you again?

**SPINAL CORD INJURY SUBJECT SCREENING FORM HUM68800**

---

DEMOGRAPHICS (from SCI registry/medical record):

SEX: Male Female

TIME SINCE INJURY:

WILLING TO TRAVEL: YES NO

LEVEL OF INJURY/ASIA SCALE:

---

Use the following script when screening a potential participant.

1. Can you tell me about the cause of your injury?

Listen to their brief response.

2. Due to your SCI, do you have any problems with your bladder and bowel functions?

Listen to their brief response.

3. Do you have a caregiver, someone who works with you to meet at least some of your needs?

Listen to their brief response.

4. Are you able to travel to Ann Arbor to meet with one of our interviewers for this study?

IF YES, skip to Question 6.

IF NO, proceed to the following.

5. We may be able to arrange for one of our interviewers to come to your home and interview you there. Would that be OK?

IF YES, proceed to the following.

IF NO, ask if there is an alternative since neither Ann Arbor nor their home seems to work for them.

6. Do you have any questions for me about the project?

Answer any questions. Once complete, ask them to hold a moment and proceed to the following page.



**SPINAL CORD INJURY SUBJECT SCREENING FORM HUM68800**

---

Address the following from your point of view:

DO NOT ASK THIS QUESTION OF THE POTENTIAL SUBJECT – SCREENER ANSWERS HIM/HERSELF:

Potential subject has the ability to express themselves regarding their experiences: YES NO

---

IF YES, proceed to the following.

Thank you for your time and for answering my questions. I feel you would be a good fit for our study and someone will contact you soon to set up an appointment to conduct the interview. Is the phone number I called today the best way to reach you?

Record their preferred phone number and proceed to the following.

We have both male and female interviewers. Do you have a preference for your interview?

Circle one: Male Female No preference

Assure them that someone will be contacting them soon to schedule an interview, thank them again for their time, and hang up.

---

IF NO, proceed to the following.

Thank you for your time and for answering my questions. I would like to discuss your case with our research team. We will contact you with a decision regarding your eligibility within the next two weeks. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

AT THIS TIME, SUBJECT IS ADMITTED TO THE STUDY, PENDING INFORMED CONSENT: YES NO

SCREENER NAME:

**NOTE:** If the potential subject passes screening and agrees to be a part of the study, they must be assigned a unique subject identification number. **Please see Study Coordinator (E. Rohn) to acquire the appropriate number in the queue.**

**CAREGIVER SUBJECT SCREENING FORM HUM68800**

---

DEMOGRAPHICS:

SEX:    Male    Female

WILLING TO TRAVEL:    YES    NO

---

Use the following script when screening a potential participant.

1. As a caregiver, are you currently providing care for someone with a spinal cord injury?

Listen to their brief response.

2. Due to that person's SCI, do you assist him/her in managing their bladder and bowel functions?

Listen to their brief response.

3. Are you able to travel to Ann Arbor to meet with one of our interviewers for this study?

IF YES, skip to Question 5.

IF NO, proceed to the following.

4. We may be able to arrange for one of our interviewers to come to your home and interview you there. Would that be OK?

IF YES, proceed to the following.

IF NO, ask if there is an alternative since neither Ann Arbor nor their home seems to work for them.

5. Do you have any questions for me about the project?

Answer any questions. Once complete, ask them to hold a moment and proceed to the following page.

**CAREGIVER SUBJECT SCREENING FORM HUM68800**

---

Address the following from your point of view.

DO NOT ASK THIS QUESTION OF THE POTENTIAL SUBJECT – SCREENER ANSWERS HIM/HERSELF:

Potential subject is currently a caregiver for someone with SCI	YES	NO
Potential subject assists that person with SCI with their bladder and bowel	YES	NO
Potential subject has the ability to express themselves regarding their experiences:	YES	NO

---

IF ALL ARE YES, proceed to the following.

Thank you for your time and for answering my questions. I feel you would be a good fit for our study and someone will contact you soon to set up an appointment to conduct the interview. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

IF ONE OR MORE ARE NO, proceed to the following.

Thank you for your time and for answering my questions. I would like to discuss your case with our research team. We will contact you with a decision regarding your eligibility within the next two weeks. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

AT THIS TIME, SUBJECT IS ADMITTED TO THE STUDY, PENDING INFORMED CONSENT: YES NO

SCREENER NAME:

**NOTE:** If the potential subject passes screening and agrees to be a part of the study, they must be assigned a unique subject identification number. **Please see Study Coordinator (E. Rohn) to acquire the appropriate number in the queue.**



The **University of Michigan** in coordination with the **Department of Defense** is conducting a new study to learn more about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life.

## Who can participate in this study?

- You are a caregiver for someone with a spinal cord injury.
- You are between the ages of 18 and 70.
- You have provided care for that person for more than 30 days.
- Able to speak and understand English.

## What does the study involve?

- A one-on-one interview by telephone, in the clinic or your home lasting 30 – 60 minutes.

**If you are eligible and complete the research, you will be compensated \$25.**

**Principal Investigator:** Denise Tate, Ph.D., ABPP, Dept of Physical Medicine & Rehabilitation

**Project Manager:** Edward Rohn, MA, Dept of Physical Medicine & Rehabilitation

**To learn more,** contact our research office at (734) 763-6189 or [DOD-SCISStudy@umich.edu](mailto:DOD-SCISStudy@umich.edu)

Dod Bowel-Bladder Study (734) 763-6189 DOD-SCISStudy@umich.edu	Dod Bowel-Bladder Study (734) 763-6189 DOD-	Dod Bowel-Bladder Study (734) 763-6189 DOD-SCISStudy@umich.edu	Dod Bowel-Bladder Study (734) 763-6189 DOD-SCISStudy@umich.edu	Dod Bowel-Bladder Study (734) 763-6189 DOD-SCISStudy@umich.edu	Dod Bowel-Bladder Study (734) 763-6189 DOD-SCISStudy@umich.edu
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## Oral Recruitment Script for Veterans with SCI

Use the following script when telephoning a potential participant.

Hello, my name is XXX and I am calling from the Ann Arbor VA Department of Physical Medicine and Rehabilitation. Dr. DiPonio is the principal investigator here at the VA for this study and we sent you a letter a few weeks ago about a new study. I wanted to tell you a little more about the new study and to see if you would be interested in joining. Would that be OK?

IF NO, thank them for their participation and hang up.

IF YES, proceed to the following:

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. The study is asking veterans with SCI and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. Would you be interested in learning more about this study?

IF NO, thank them for taking the time to hear about it and hang up.

IF YES, proceed to the following:

In this study you will do a one-on-one interview, in person here at the VA, talking in depth about issues such as the kinds of problems you experience with bowel and bladder and how these affect your independence, coping with problems, or how taking care of bowel and bladder functions affects intimate and family relationships. The interview will take 60 – 90 minutes to do. You will also complete a series of questionnaires about your mood, the quality of care you get, and your bowel and bladder program and any specific problems you may have. That should take another 60 – 80 minutes.

Does this sound like something you would be interested in doing?

IF NO, thank them and hang up.

IF YES, proceed to the following.

If you have time right now, let's set up a time for you to come to the VA and I will go over the informed consent form and answer any questions you have. When we are done with that, you will do your interview and fill out the questionnaire.

IF YES, proceed to scheduling.

IF NO, schedule a time to call back and schedule interview.

Thank you for agreeing to join this study!

## Oral Recruitment Script for Caregivers

Use the following script when telephoning a potential participant.

Hello, my name is XXX and I am calling from the Ann Arbor VA Department of Physical Medicine and Rehabilitation. Dr. DiPonio is the principal investigator here at the VA for this study and we sent you a letter a few weeks ago about a new study. I wanted to tell you a little more about the new study and to see if you would be interested in joining. Would that be OK?

IF NO, thank them for their participation and hang up.

IF YES, proceed to the following:

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. The study is asking veterans with SCI and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. Would you be interested in learning more about this study?

IF NO, thank them for taking the time to hear about it and hang up.

IF YES, proceed to the following:

In this study you will do a one-on-one interview, in person here at the VA, talking in depth about issues such as the kinds of problems you experience with bowel and bladder and how these affect your independence, coping with problems, or how taking care of bowel and bladder functions affects intimate and family relationships. Does this sound like something you would be interested in doing?

IF NO, thank them and hang up.

IF YES, proceed to the following.

If you have time right now, let's set up a time for you to come to the VA. I will meet with you to go over the informed consent form and answer any questions you have. When we are done with that, you will do your interview with the interviewer.

IF YES, proceed to scheduling.

IF NO, schedule a time to call back and schedule interview.

Thank you for agreeing to join this study!

SUBJECT ID#:

DATE:

**SPINAL CORD INJURY SUBJECT SCREENING FORM 2013-010067**

---

DEMOGRAPHICS (from SCI registry/medical record):

SEX:    Male    Female

TIME SINCE INJURY:

WILLING TO TRAVEL:    YES    NO

LEVEL OF INJURY/ASIA SCALE:

---

Use the following script when screening a potential participant.

1. Can you tell me about the cause of your injury?

Listen to their brief response.

2. Due to your SCI, do you have any problems with your bladder and bowel functions?

Listen to their brief response.

3. Do you have a caregiver, someone who works with you to meet at least some of your needs?

Listen to their brief response.

4. Our research study takes place at the Ann Arbor VA and you would need to meet one of our interviewers there for this study. Will you be able to meet one of us there?

IF YES, proceed to the following.

IF NO, explain to the potential subject the need to conduct all research at the VA. If the response is still "NO", thank them for their time and inform them that we cannot enroll them in the study.

5. Do you have any questions for me about the project?

Answer any questions. Once complete, ask them to hold a moment and proceed to the following page.



SUBJECT ID#:

DATE:

**SPINAL CORD INJURY SUBJECT SCREENING FORM HUM68800**

---

Address the following from your point of view:

DO NOT ASK THIS QUESTION OF THE POTENTIAL SUBJECT – SCREENER ANSWERS HIM/HERSELF:

Potential subject has the ability to express themselves regarding their experiences:      YES      NO

---

IF YES, proceed to the following.

Thank you for your time and for answering my questions. I feel you would be a good fit for our study and someone will contact you soon to set up an appointment to conduct the interview. Is the phone number I called today the best way to reach you?

Record their preferred phone number and proceed to the following.

We have both male and female interviewers. Do you have a preference for your interview?

Circle one:      Male              Female              No preference

Assure them that someone will be contacting them soon to schedule an interview, thank them again for their time, and hang up.

---

IF NO, proceed to the following.

Thank you for your time and for answering my questions. I would like to discuss your case with our research team. We will contact you with a decision regarding your eligibility within the next two weeks. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

AT THIS TIME, SUBJECT IS ADMITTED TO THE STUDY, PENDING INFORMED CONSENT:      YES      NO

SCREENER NAME:

**NOTE:** If the potential subject passes screening and agrees to be a part of the study, they must be assigned a unique subject identification number. **Please see Study Coordinator (E. Rohn) to acquire the appropriate number in the queue.**

SUBJECT ID#:

DATE:

**CAREGIVER SUBJECT SCREENING FORM 2013-010067**

---

DEMOGRAPHICS:

SEX:    Male    Female

WILLING TO TRAVEL:    YES    NO

---

Use the following script when screening a potential participant.

1. As a caregiver, are you currently providing care for someone with a spinal cord injury?

Listen to their brief response.

2. Due to that person's SCI, do you assist him/her in managing their bladder and bowel functions?

Listen to their brief response.

3. Our research study takes place at the Ann Arbor VA and you would need to meet one of our interviewers there for this study. Will you be able to meet one of us there?

IF YES, proceed to the following.

IF NO, explain to the potential subject the need to conduct all research at the VA. If the response is still "NO", thank them for their time and inform them that we cannot enroll them in the study.

4. Do you have any questions for me about the project?

Answer any questions. Once complete, ask them to hold a moment and proceed to the following page.

SUBJECT ID#:

DATE:

**CAREGIVER SUBJECT SCREENING FORM HUM68800**

---

Address the following from your point of view.

DO NOT ASK THIS QUESTION OF THE POTENTIAL SUBJECT – SCREENER ANSWERS HIM/HERSELF:

Potential subject is currently a caregiver for someone with SCI	YES	NO
Potential subject assists that person with SCI with their bladder and bowel	YES	NO
Potential subject has the ability to express themselves regarding their experiences:	YES	NO

---

IF ALL ARE YES, proceed to the following.

Thank you for your time and for answering my questions. I feel you would be a good fit for our study and someone will contact you soon to set up an appointment to conduct the interview. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

IF ONE OR MORE ARE NO, proceed to the following.

Thank you for your time and for answering my questions. I would like to discuss your case with our research team. We will contact you with a decision regarding your eligibility within the next two weeks. Is the phone number I called today the best way to reach you?

Record their preferred phone number, thank them again for their time, and hang up.

---

AT THIS TIME, SUBJECT IS ADMITTED TO THE STUDY, PENDING INFORMED CONSENT: YES NO

SCREENER NAME:

**NOTE:** If the potential subject passes screening and agrees to be a part of the study, they must be assigned a unique subject identification number. **Please see Study Coordinator (E. Rohn) to acquire the appropriate number in the queue.**

# RESEARCH PARTICIPANTS NEEDED

---

The VA Ann Arbor Health System is conducting a new study to learn more about how neurogenic (or a loss of control of) bladder and bowel in people with spinal cord injury affect quality of life.



## **Who can participate in this study?**

- Caregivers of someone with a spinal cord injury who have been a caregiver for more than 30 days;
- Between the ages of 18 and 70 years;
- Able to speak and understand English;
- And able and willing to travel the Ann Arbor VA.

## **What does the study involve?**

A one-on-one interview at the Ann Arbor VA. This will take 60 – 90 minutes.

## **Who do I contact to learn more?**

- E-mail to the researchers at [ejrohn@med.umich.edu](mailto:ejrohn@med.umich.edu)
- Call the researchers at (734)763-6189 and mention the “DOD SCI Study”

**Principal Investigator: Lisa DiPonio, MD**

## 2. CONSENT & INTERVIEW PROCEDURES

1. Interviewers schedule their own interview meetings and should work together on scheduling.
  - a. **NOTE:** Measures and interviews MUST be completed within two weeks of each other.
  - b. The DOD Project Outlook calendar should be added to your Outlook and used to help us monitor the flow of data collection – especially in instances where two interviewers are interviewing the same person (there is a two-week deadline between qualitative and questionnaire interviews!) – **CONFIRM INTERVIEWS 1 to 2 DAYS IN ADVANCE!**
2. Qualitative Interviews **MUST** be conducted face-to-face, unless the you obtain prior approval.
  - a. UM Subjects may be interviewed at Burlington, at the subject's home, or at their clinic – as long as quiet and confidentiality can be reasonably assured.
  - b. Space at Burlington may be "booked" on the shared Outlook calendars. If you do not have access to the shared calendars, please contact the study coordinator for assistance
  - c. VA Subjects MUST be interviewed at the Ann Arbor VA, in our secure interview office. Access to this office is through the Study Coordinator (Rohn), Dr. DiPonio, or Dr. Roth.
  - d. Any VA activities should be communicated as soon as possible to the physicians that use that room – DiPonio, Roth, Werner. Rohn can assist in this communication.
3. Questionnaires must be completed within two weeks following the qualitative interview!
  - a. UM Subjects may complete questionnaire in person at any secure location or by phone.
  - b. VA Subjects **MUST** complete measures face-to-face in our secure interview office.
4. Prior to the interview
  - a. Print the appropriate consent forms, interview guides, quantitative measures packet, response cards & compensation form. These are here below and on the shared drive.
  - b. Print a second copy of the appropriate consent form for the subject to keep.
  - c. Check out the proper equipment through the study coordinator, preferably the day-of.
    - i. UM equipment is stored in the study coordinator's office
    - ii. VA equipment is stored in our office there and **CAN NOT LEAVE THE VA!**
5. At the interview
  - a. **CONSENT MUST BE CONDUCTED PRIOR TO ANY DATA COLLECTION!** Consent is conducted by the Qualitative Interviewer.
    - i. Use appropriate consent form for group (SCI or Caregiver) AND site (UM or VA)
    - ii. Consents **MUST UTILIZE** the appropriate "Informed Consent Checklist" – the VA in particular will audit these, so they **MUST** be completed.
  - b. Conduct the qualitative interview using the appropriate Interview Guide
    - i. Be sure to fill out and give the Appointment Reminder Form to the subject.
    - ii. Be sure to fill out Interview Receipt document, with a copy for us and for subject
    - iii. Be sure to document whether an SCI patient's Caregiver wishes to participate.
  - c. Conduct the quantitative measures using the correct Questionnaire Packet and **CARDS**
    - i. Ask qual interviewer to provide copy of the measures to the subject.
    - ii. Measures can (and ideally should) be completed in REDCap to ease data entry.

## UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

### NAME OF STUDY AND RESEARCHERS

**Title of Project:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI

**Principal Investigator:** Denise G. Tate, PhD, ABPP

**Co-Investigators:** Lisa DiPonio, M.D., Anne Pelletier-Cameron, MD, Gianna Rodriguez, MD, Randy Roth, PhD, Claire Kalpakjian, PhD, and Martin Forchheimer, MPP

### GENERAL INFORMATION

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. This study is funded by the U.S. Department of Defense. The study is asking persons with spinal cord injury (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. All participants will be interviewed by an experienced interviewer about their experiences. To learn more about these, we are asking people with spinal cord injury to be involved in a one-on-one interview, one focus group session and to complete questionnaires.

A total of 60 people (40 people with spinal cord injury and 20 caregivers of someone with a spinal cord injury) will participate in this research study. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study. People with a spinal cord injury will be either within 12 months post-injury or 10 or more years post-injury.

The study will involve a **one-on-one interview**, talking in depth about issues such as the kinds of problems you experience with bowel and bladder, how it affects your independence, coping with problems, or how taking care of bowel and bladder functions affect intimate and family relationships. The interview will take 60 – 90 minutes to do and will be audio-recorded. This is because the researchers will carefully go over what you talked about during the interview. You will also complete a **series of questionnaires** about your mood, the quality of care you get, and any specific problems you have with your bowel and bladder. This will be done after you complete the interview and this should take another 45 – 60 minutes. If you prefer, you can take the questionnaires home with you and mail them back. Or someone can call you later and do it over the phone. It is your choice and should be done within two weeks from the time of the interview.

Some people who do the telephone interviews will be invited to also participate in a **focus group** which will take 60 – 90 minutes to complete. Not everyone will be invited to be in the focus group. If you are invited and choose to participate, you will sign another consent form. During the focus group, you will share your thoughts about the same kinds of issues you were interviewed about. Below are three options to choose for this study; each one is a little different so read your choices carefully. Please put your initials next to your choice (you will choose only one option).

- **Option 1:** I agree to be a part of the one-on-one interview and questionnaires AND, if I am selected, I also agree to be contacted about participating in the focus group. \_\_\_\_\_ *initials*
- **Option 2:** I agree to do the one-on-one interview and questionnaires ONLY. \_\_\_\_\_ *initials*
- **Option 3:** I agree to be part of the focus group ONLY. \_\_\_\_\_ *initials*

The **risks** in this study are related to privacy and confidentiality. To protect your confidentiality, during the interviews, you will not use your name or other information that will identify you. We will carefully check the transcripts from the interview recording to erase anything else that may identify you. Your name will also not be on any research paperwork. Instead, your name will be connected to an anonymous study number that will be on the paperwork. To protect your privacy, the one-on-one interviews will take place at your house, over the phone or in a private room next to the clinic. We will also need to review your medical record to find out more about your spinal cord injury treatment related to bowel and bladder care.

There are no direct benefits to you for taking part in this study. On the other hand, other people with SCI may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life. This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way. There is no charge to you or your health insurance for being in this study. You will receive \$25 after completing the interview. The University of Michigan accounting department will need your name, address, and payment amount for tax reporting purposes.

### **AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION**

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to take part in the study. Information about you may be obtained from any hospital, doctor, and other health care provider involved in your care, including:

- All hospital records relating to your spinal cord injury, the treatment you have received, and your response to the treatment

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- As the sponsor of this research, the Department of Defense may access the research records.
- Study sponsors or funders, or safety monitors or committees, may need the information to, make sure the study is done safely and properly, or analyze the results of the study.
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, payment amount, and related information for tax reporting purposes.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed. Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities. (This information would not include your name or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System's privacy policies. For more information see <http://www.med.umich.edu/hipaa/npp.htm>. Note that once your information has been shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by contacting the researchers listed below.

*Your signature in the next section means that you have received copies of all of the following documents:*

☒ This "Consent to be Part of a Research Study" document. (Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)

☐ Other (specify): \_\_\_\_\_

### CONTACT INFORMATION

**To find out more about the study, ask a question or express a concern about the study or if you feel you have experienced any harm from the study contact one of the following:**

Principal Investigator: Denise Tate, Ph.D.

Mailing Address: 300 N. Ingalls, NI209, Ann Arbor, MI 48109-5491

Telephone: 734-763-0971 (Office)

Study Coordinators: Andrea Nevedal, Ph.D., Edward Rohn, MA and Connie Pines

Mailing Address: 300 N. Ingalls, NI209, Ann Arbor, MI 48109-5491

Telephone: 734-763-0971 (Office)

Email: [DOD-SCIStudy@umich.edu](mailto:DOD-SCIStudy@umich.edu)

University of Michigan Compliance Help Line at 1-888-296-2481 or if you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-888-296-2481

University of Michigan Medical School Institutional Review Board (IRBMED)  
2800 Plymouth Road  
Building 520, Room 3214G  
Ann Arbor, MI 48109-2800  
734-763-4768  
E-mail: [irbmed@umich.edu](mailto:irbmed@umich.edu)



## SIGNATURES

### Research Subject:

*I understand the information printed on this form. My questions so far have been answered.*

Signature of Subject: \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_

Patient ID: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

### Legal Representative (if applicable):

Signature of Person Legally  
Authorized to Give Consent \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Check Relationship to Subject:

☐ Parent ☐ Spouse ☐ Child ☐ Sibling ☐ Legal Guardian ☐ Other: \_\_\_\_\_

*If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.*

Reason subject is unable to sign for self: \_\_\_\_\_  
\_\_\_\_\_

## UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

### NAME OF STUDY AND RESEARCHERS

**Title of Project:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI

**Principal Investigator:** Denise G. Tate, PhD, ABPP

**Co-Investigators:** Lisa DiPonio, M.D., Anne Pelletier-Cameron, MD, Gianna Rodriguez, MD, Randy Roth, PhD, Claire Kalpakjian, PhD, and Martin Forchheimer, MPP

### GENERAL INFORMATION

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. This study is funded by the U.S. Department of Defense. The study is asking persons with SCI (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. All participants will be interviewed by an experienced interviewer about their experiences. To learn more about these, we are asking people with spinal cord injury and caregivers to be involved in a one-on-one interview, one focus group session and to complete questionnaires.

A total of 60 people (40 people with spinal cord injury and 20 caregivers of someone with a spinal cord injury) will participate in this research study. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study. Caregivers of someone with a spinal cord injury will have worked with someone with SCI for at least 30 days to be eligible and can be a family member or non-family member.

The study will involve a **one-on-one interview**, talking in depth about issues you experience as a caregiver of someone with a spinal cord injury, such as the kinds of problems the person you care for has with bowel and bladder, how it affects their independence, coping with problems, or how taking care of bowel and bladder functions affects relationships. The interview will take 60 – 90 minutes to do and will be audio-recorded. This is because the researchers will carefully go over what you talked about during the interview.

Some people who do the telephone interviews will also be invited to participate in a **focus group**, which will take 60 – 90 minutes to complete. Not everyone will be invited to be in a focus group. During the focus group, you will share your thoughts about the same kinds of issues you were interviewed about. If you are invited and choose to participate in the focus group, you will sign another consent form.

Below are three options to choose for this study; each one is a little different so read your choices carefully. Please put your initials next to your choice (you will choose only one option).

- **Option 1:** I agree to be a part of the one-on-one interview AND, if I am selected, I also agree to be contacted about participating in the focus group. \_\_\_\_\_ *initials*
- **Option 2:** I agree to do the one-on-one interview ONLY. \_\_\_\_\_ *initials*
- **Option 3:** I agree to be part of the focus group ONLY. \_\_\_\_\_ *initials*

The **risks** in this study are related to privacy and confidentiality. To protect your confidentiality, during the interviews, you or the interviewer will not use your name or other information that will identify you. We will carefully check the transcripts from the interview recording to erase anything else that may identify you. Your name will also not be on any research paperwork. Instead, your name will be connected to an anonymous study number that will be on the paperwork. To protect your privacy, the one-on-one interviews will take place at your house, over the phone or in a private room next to the clinic. As the sponsor of this research, the Department of Defense may access the research records.

There are no direct benefits to you for taking part in this study. On the other hand, other people with SCI may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life. This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way. There is no charge to you or your health insurance for being in this study. You will receive \$25 after completing the interview. The University of Michigan accounting department will need your name, address, and payment amount for tax reporting purposes.

*Your signature in the next section means that you have received copies of all of the following documents:*

- ☐ This "Consent to be Part of a Research Study" document. *(Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)*

### CONTACT INFORMATION

**To find out more about the study, ask a question or express a concern about the study or if you feel you have experienced any harm from the study contact one of the following:**

Principal Investigator: Denise Tate, Ph.D.

Mailing Address: 300 N. Ingalls, NI209, Ann Arbor, MI 48109-5491

Telephone: 734-763-0971 (Office)

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University of Michigan Compliance Help Line at 1-888-296-2481 or if you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-888-296-2481

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2800 Plymouth Road  
Building 520, Room 3214G  
Ann Arbor, MI 48109-2800  
734-763-4768  
E-mail: [irbmed@umich.edu](mailto:irbmed@umich.edu)

## SIGNATURES

### Research Subject:

*I understand the information printed on this form. My questions so far have been answered.*

Signature of Subject: \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_

Patient ID: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

### Legal Representative (if applicable):

Signature of Person Legally  
Authorized to Give Consent \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Check Relationship to Subject:

☐ Parent ☐ Spouse ☐ Child ☐ Sibling ☐ Legal Guardian ☐ Other: \_\_\_\_\_

*If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.*

Reason subject is unable to sign for self: \_\_\_\_\_  
\_\_\_\_\_

## Oral Consent Elements

Read over the phone (with waiver of documentation)

### For Interviews

Revised April 17, 2013

**Subject Name:** \_\_\_\_\_

**Date provided to subject:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affects health, quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. This study is funded by the U.S. Department of Defense. The study is asking people with SCI (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder and the associated problems.

To learn more about these, we are asking people with spinal cord injury and caregivers to be involved in a one-on-one interview, a focus group session and for those participants with SCI, to complete questionnaires.

A total of 60 people (40 people with spinal cord injury and 20 caregivers of someone with a spinal cord injury) will participate in this research study. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study.

### FOR SCI ONLY

People with a spinal cord injury will have had their SCI during the last 12 months or be 10 or more years post-injury.

The study will involve a **one-on-one interview**, talking in depth about issues such as the kinds of problems you experience with bowel and bladder, how it affects your independence, coping with problems, or how taking care of bowel and bladder functions affect intimate and family relationships. The interview will take 60 – 90 minutes to do and will be audio-recorded. This is because the researchers will carefully go over what you talked about during the interview. The one-on-one interview will take place at your house, over the phone or in a private room next to the clinic. You will also complete a **series of questionnaires** about your mood, the quality of care you get, and any specific problems you have with your bowel and bladder. This will be done after you complete the interview and this should take another 45 – 60 minutes. If you prefer, you can take the questionnaires home with you and mail them back. Or someone can call you later and do it over the phone. It is your choice and should be done within two weeks from the time of the interview.

### (HIPAA Authorization)

We will also need to review your medical record to find out more about your spinal cord injury treatment related to bowel and bladder care. There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.

- The Department of Defense may request to see information about you as part of this study.
- Study sponsors or funders, or safety monitors or committees, may need the information to, make sure the study is done safely and properly, or analyze the results of the study.
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, payment amount, and related information for tax reporting purposes.

#### FOR CAREGIVERS ONLY

Caregivers of someone with a spinal cord injury will have worked with someone for at least 30 days to be eligible. They can be a family member or non-family members.

The study will involve a **one-on-one interview**, talking in depth about issues you experience as a caregiver of someone with a spinal cord injury, such as the kinds of problems the person you care for has with bowel and bladder, how it affects their independence, coping with problems, or how taking care of bowel and bladder functions affects relationships. The interview will take 60 – 90 minutes to do and will be audio-recorded. This is because the researchers will carefully go over what you talked about during the interview. The one-on-one interview will take place at your house, over the phone or in a private room next to the clinic.

#### FOR BOTH GROUPS

Some people who do the telephone interviews will be invited to also participate in a **focus group** which will take 60 – 90 minutes to complete. Not everyone will be invited to be in the focus group. If you are invited and choose to participate, you will sign another consent form. During the focus group, you will share your thoughts about the same kinds of issues you were interviewed about.

The **risks** in this study are related to privacy and confidentiality. To protect your confidentiality, during the interviews, you will not use your name or other information that will identify you. We will carefully check the transcripts from the interview recording to erase anything else that may identify you. Your name will also not be on any research paperwork. Instead, your name will be connected to an anonymous study number that will be on the paperwork. To protect your privacy, the one-on-one interviews will take place at your house, over the phone or in a private room next to the clinic. We will also need to review your medical record to find out more about your spinal cord injury treatment related to bowel and bladder care.

There are no direct benefits to you for taking part in this study. On the other hand, other people with spinal cord injury may benefit by the information we learn in terms of how to best optimize treatments and reduce a negative impact on overall quality of life. This research is voluntary. You do not have to take part in this study.

Choosing not to be in this research study will not affect your care in any way. There is no charge to you or your health insurance for being in this study. You will receive \$25 for completing the interview. The University of Michigan accounting department will need your name, address, payment amount, and related information for tax reporting purposes.

I will read three options you will choose from for this study and you will choose only one option.

- **Option 1:** I agree to be a part of the one-on-one interview (and questionnaires if I have a spinal cord injury) AND, if I am selected, I also agree to be contacted about participating in the focus group..
- **Option 2:** I agree to do the one-on-one interview ONLY (and questionnaires if I have a spinal cord injury).
- **Option 3:** I agree to be part of the focus group, if I am invited, ONLY.

**Which option would you prefer?** \_\_\_\_\_

Participant consents to join the study                      Yes      No

Interviewer signature and date: \_\_\_\_\_

# Obtaining Informed Consent Checklist RCO 2/28/13

>Document to be completed for each consent obtained and filed with the original informed consent document<

RESEARCH STUDY IDENTIFICATION (Required information)
STUDY TITLE: <u>Psychological &amp; Behavioral Factors Associated with Bowel &amp; Bladder Management after SCI</u>
PI: <u>Denise Tate, PhD</u>
NAME OF STUDY TEAM MEMBER OBTAINING CONSENT: _____
ROLE OF STUDY TEAM MEMBER OBTAINING CONSENT: _____

RESEARCH SUBJECT IDENTIFICATION: (Required information)				
			N/A	/ /
Last Name	First Name	Mid. Init.	Last-4 SSN	Date (mm/dd/yy)

A.	<< Date ALL required SIGNATURES (Subject, Witness (If required by IRB) and Person Obtaining Consent), their PRINTED NAMES and the DATES they signed the informed consent document (ICD) have been checked and appear in the proper location
B.	<< Date and Time of Day (ICD) was reviewed and deemed complete and valid
C.	<< Date and Time of the subject's first study activity or involvement
	Verify and Initial each of the following 12 requirements.
1.	Informed consent and HIPPA authorization was obtained from this subject prior to study participation. Note: Recorded Date and Time of Day (ICD) was reviewed and deemed complete and valid (B.) MUST be prior to recorded Date and Time of Day Subject began study participation (C).
2.	I have been officially added to the IRB and accepted my role in the study, designating me as an authorized agent of the PI and qualified to obtain consent for this study.
3.	This prospective subject was given adequate time necessary to carefully and fully read the Informed consent document (ICD) and all questions were answered to his/her satisfaction.
4.	All aspects of this subject's study involvement, including the purpose of the study, known and potential risks, possible benefits and alternatives to study participation were explained and discussed prior to subject signing the ICD.
5. N/A	If required, an enrollment note and scanned Consent Form image will be entered in the patient's electronic medical record (CPRS).
6.	Subject has been consented using the most recently approved, UM logo date-stamped version of the appropriate consent form (SCI or Caregiver).
7.	A copy of the fully-completed signed, original informed consent document has been issued to this subject and he/she was instructed to retain that copy for reference and to ask any and all questions that might arise throughout his/her study involvement.
8.	The subject has been shown where in the ICD to locate study team phone number(s) and the phone number of the UM IRB Coordinator. The subject has been reminded to call with any questions or concerns.
9.	The subject has been informed that participation is entirely voluntary and that they may withdraw their participation at any time and for any reason.
10.	I'm aware that original ICDs and all copies must be printed and issued as single-sided documents and that the original signed ICD must be kept in the study coordinator's office.
11.	It is my opinion (person obtaining consent) and the opinion of the Principal Investigator that this subject is capable of understanding the informed consent document and what his/her overall involvement in the study will entail.
12.	I know I can contact the UM IRB Coordinator at 734.763.4768 or the Research Compliance Help Line at 1.888.296.2481 if I have questions or concerns regarding the consent of this or any individual considering study participation.



# Department of Veterans Affairs Research Consent Form

**VA AAHS Research IRB**  
Approved 01/09/2014  
Expires 01/08/2015



**Title of Study:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: VETERANS

**Principal Investigator:** Lisa DiPonio, MD

**VAMC:** VA Ann Arbor  
Healthcare System

## PURPOSE OF RESEARCH STUDY:

We are conducting a study about how neurogenic bladder and bowel in people with spinal cord injury (SCI) affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. The study is asking veterans with SCI and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction.

## DESCRIPTION:

This study is sponsored by the U.S. Department of Defense and being done in collaboration with the University of Michigan. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study. People with an SCI will be either less than 12 months post-injury or 10 or more years post-injury. Veterans with SCI who receive care at the VA Ann Arbor Health Care System were invited to join this study. Twenty veterans with SCI will participate in this study. You must be able to travel to the VA to participate in the interview.

In this study, you will complete a one-on-one interview about your personal experience as a veteran with SCI. The interview will cover topics like how bowel and bladder problems affect things like quality of life, independence and community participation. The interview will take place in a private room and will take about 60 to 90 minutes. Then you will complete a set of questionnaires about your mood, the quality of care you get, and any specific problems you have with your bowel and bladder. This will be done after you complete the interview and this should take another 45 to 60 minutes. If needed, questionnaires can be completed on another day as long as it happens within one week after your interview. You can take the questionnaires home with you and mail them back or they can be completed over the telephone with the study coordinator. The total time to complete the study is about 1 hour and 45 minutes to 2 and half hours.

The one-on-one interviews will be audio-recorded and then transcribed into a document. This is because the researchers will carefully go over what you talked about to learn more about bowel and bladder and quality of life. We will also need to review your medical record to find out more about your SCI treatment related to bowel and bladder care.

We will also ask you if you know of any caregivers of people with SCI who may like to be in this study and do a one-on-one interview. You can recommend your own caregiver too. If there is someone you think might be interested you can give us their name and phone number or you can give them our contact information and they can call us. If you can't think of any caregiver that might be interested, this will not affect your participation in this study.

After your interview, if you agree, we may call you again to see if you are interested in participating in a focus group to talk more about the things you told us in your interview. Not everyone will be invited to be in the focus group. If we do invite you, we will call you back within a month after your one-on-one interview. The focus group will take place at the University of Michigan. For the focus group, about 10 other people with SCI will meet and talk about their experience, led by a group facilitator. If you are interested, we will give you contact information for the UM study team and you can call them to learn more about being in the study. If you agree to be in the focus group, you will sign a different consent form from the University of Michigan.

## RESEARCH SUBJECT IDENTIFICATION: (Required information)

				/ /
Last Name	First Name	Mid. Init.	Last-4 SSN	Date (mm/dd/yy)

# Department of Veterans Affairs Research Consent Form

**VA AAHS Research IRB**  
Approved 01/09/2014  
Expires 01/08/2015



**Title of Study:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: VETERANS

**Principal Investigator:** Lisa DiPonio, MD

**VAMC:** VA Ann Arbor  
Healthcare System

**Please check one of the boxes below to tell us whether it is OK to see if you are interested in learning more about a focus group.**

- ☐ Yes, it is OK to call me  
☐ No, please do not call me

## **RISKS:**

The risks of participating in this study are very minimal. There is a risk of a loss of confidentiality of your research records. Some questions during the interview may make you uncomfortable or feel embarrassed. You may choose not to answer any question or stop the interview at any time with no penalty to you. If any questions on the surveys make you uncomfortable, you may skip them too. There may be other risks that are unforeseeable at this time.

## **BENEFITS:**

You are not likely to directly benefit from participating in this study. On the other hand, other people with SCI may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life.

## **ALTERNATE COURSES OF ACTION:**

This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way and you will not lose any benefits that you may be entitled to. If you choose to end the study early, you may freely do so with no

## **STATEMENT OF RESEARCH RESULTS:**

To protect your privacy and confidentiality, during the interviews we will ask that as much as possible, you don't use your name to say anything that identifies who you are, like where you live. But just to be sure, the person who transcribes the interview will remove anything you may have said that identifies you. Finally, we will read each transcript carefully to make sure nothing was missed that may identify you. For any study data, like a form or the transcription of your interview, your name will be connected to an anonymous study number that will be on the study paperwork. The link between your name and that number will be kept separate from the study forms. Nothing you tell us during the interview will be shared with any person outside the researchers or any other study participant. For example, if your caregiver joins the study, we will not tell them anything about what you told us and vice versa. We also will not tell you if someone you told us about joined the study.

This study is taking place in collaboration with the University of Michigan which is the lead center. Once your interview has been transcribed into a document it will be sent to the University of Michigan; the audio recording of your interview will NOT be sent. That recording will stay at the VA. The document will not contain any information that will identify who you are. Instead it will have an anonymous code number and the link between your name and that code number will stay at the VA on a protected electronic file. If you also complete the questionnaires, these too will be sent to the University of Michigan with the same code number assigned to you. Researchers at the University of Michigan will protect your data by storing paper files in locked cabinets inside locked offices; only the researchers will have a key and be able to see these files. When your data is put into a database on a computer, it will be stored on a password-protected server and only the researchers will be able to open the folder. Eventually, your data will be combined with everyone who is in this study and like you, they will all have codes to keep their information confidential.

# Department of Veterans Affairs Research Consent Form

**VA AAHS Research IRB**  
Approved 01/09/2014  
Expires 01/08/2015



**Title of Study:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: VETERANS

**Principal Investigator:** Lisa DiPonio, MD

**VAMC:** VA Ann Arbor  
Healthcare System

If results of this study are reported in medical journals or at meetings, you will not be identified by name, by recognizable photograph, or by any other means without your specific consent. No information by which you can be identified will be released or published unless required by law. We will let you and your physician know of any important discoveries made during this study which may affect you, your condition, or your willingness to participate in this study.

## **SPECIAL CIRCUMSTANCES:**

There will be not be any costs to you for any additional care that you receive as a participant in this research study.

## **COMPENSATION:**

When the interview and questionnaires are completed, you will receive a \$25 check in the mail as thanks for your time and willingness to share you experience in this study. The University of Michigan accounting department, which will process your payment, will need your name and address. This information will be given directly to the accounting department by the study coordinator. And it will not be associated with your study information in any way. You may decline compensation if you do not want to share this information with the University of Michigan accounting department.

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**VA AAHS Research IRB**  
Approved 01/09/2014  
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**Title of Study:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: VETERANS

**Principal Investigator:** Lisa DiPonio, MD

**VAMC:** VA Ann Arbor  
Healthcare System

## RESEARCH SUBJECT'S RIGHTS:

\_\_\_\_\_ has explained this research study and answered all questions. The risks or discomforts and possible benefits of the study have been described. Other choices of available treatment have been explained. Some veterans are required to pay co-payments for medical care and services provided by VA. These co-payment requirements will continue to apply for VA care and services that are not part of this study.

Participation in this study is entirely voluntary. You may refuse to participate. Refusal to participate will involve no penalty or loss of rights to which individuals are entitled. Participants may withdraw from this study at any time without penalty or loss of VA or other benefits. In the event that you sustain an injury or illness as a result of your participation in this VA approved research study, all necessary medical treatment (except in limited circumstances), will be provided in a VA medical facility. You will be treated for the injury at no cost to you. However, no additional compensation has been set aside. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

In case there are medical problems, an injury, or if you have questions, concerns or complaints about the research study, you can contact member(s) of the research study team: Edward Rohn, Study Coordinator, can be called at (734) 763-6189 during the day and Lisa DiPonio, MD can be contacted after hours at (734) 936-6266 (follow the prompts and enter Page ID# 10171).

You may contact the VA Human Studies coordinator at 734-845-3440 to ask questions about your rights as a research subject and to verify this study is reviewed and approved by the VA. You may also call when research study staff are not available or to discuss your questions or concerns with someone other than study staff. You may learn more about research at the VA Ann Arbor Healthcare System at [www.annarbor.research.va.gov](http://www.annarbor.research.va.gov)

I have been informed about my rights as a research subject, and I voluntarily consent to participate in this study. I will receive a signed copy of this consent form.

X \_\_\_\_\_  
Signature of Subject

X \_\_\_\_\_  
(Print Name)

X \_\_\_\_\_  
Date (mm/dd/yy)

X \_\_\_\_\_  
Signature of person obtaining consent  
(Study personnel must be approved by VA IRB.)

X \_\_\_\_\_  
(Print Name)

X \_\_\_\_\_  
Date (mm/dd/yy)

**IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086) MUST BE CONSECUTIVELY NUMBERED.**

## Department of Veterans Affairs HIPAA Authorization Form

<b>Title of Study:</b>	Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI		
<b>Principal Investigator:</b>	Lisa DiPonio, MD	VA Ann Arbor Healthcare System	

### REQUEST FOR PATIENT AUTHORIZATION FOR ACCESS TO PROTECTED HEALTH INFORMATION

1. By signing this document, you authorize the Veterans Health Administration (VHA) to provide **Lisa DiPonio, MD** and the research team permission to view and collect the following Personally Identifying Information (PII) and Protected Health Information (PHI) about you for research purposes:  
 -> ***Your name, where you live, your telephone number and email address.***
2. The research investigators will collect your PHI for the following specific research purposes:  
 -> ***To learn about my spinal cord injury and treatment.***
3. Confidentiality Statement: The confidentiality of research records that identify you as a subject will be maintained and protected as follows :-> ***Any data collected in this study will be stored separately from any information that identifies you. We will store research data in locked cabinets in locked offices and on computers that require a password that only the study team will have.***
4. You may refuse to sign this authorization and refuse to allow the disclosure of your Protected Health Information. Your refusal will not affect your ability to receive medical care or benefits at the VA Ann Arbor Healthcare System.
5. This authorization will expire at the end of the research study.
6. This authorization may be revoked at any time by sending a written request to **Lisa DiPonio, MD, 2215 Fuller Road, Ann Arbor, 48105**. If you revoke this authorization, **Lisa DiPonio, MD** and the research team can continue to use information about you that has been collected. No information will be collected after you revoke the authorization.
7. The Ann Arbor VAMC complies with the requirements of the Health Insurance Portability and Accountability Act of 1996 and its privacy regulations and all other applicable laws that protect your privacy. The research records from this study may be reviewed by the Institutional Review Board and Compliance Monitors of the Ann Arbor VAMC and by other government agencies (including, but not limited to: the Government Accounting Office, Office of Human Research Protections, VA Office of Inspector General and VA Office of Research Oversight). Individually-identifiable health information that may be disclosed under this authorization may no longer be protected by Federal laws or regulations and may be subject to re-disclosure by the recipient.
8. **You may check any of these areas of especially sensitive information that you will allow to be disclosed to the entities in the item above.**  

☐ **Alcohol abuse treatment**  
 ☐ **Drug abuse treatment**  
 ☐ **Sickle Cell Anemia**  
 ☐ **HIV infection**
9. As part of the study, we may disclose your information to the **University of Michigan** who is coordinating this study so that we can process your subject payment. We will not share any information with these persons unless they agree to keep the information confidential and use it only for the purposes related to the study.
10. As the sponsor of this research, the Department of Defense may access the research records.

X _____	[ _____ ]	X _____	X _____
Signature of Subject	<b>Last 4-SSN</b>	(Print Name)	Date (mm/dd/yy)
X _____	<u>leave blank if N.A.</u>	X _____	X _____
Signature of Personal Representative		(Print Name)	Date (mm/dd/yy)
(A Court appointed legal guardian, or a legally authorized Power of Attorney.)			



# Department of Veterans Affairs

<b>CONSENT FOR USE OF PICTURE AND/OR VOICE</b>		<b>CONSENT OF (Name)</b> ->	
<p>NOTE: The information requested on this form is solicited under the authority of title 38, United States Code. The execution of this form does not authorize disclosure of the materials specified below except for the purpose(s) stated. The specified material may be used within the VA for authorized purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as stated in the 'Routine Uses' in the "VA Privacy Act Systems of Records" published in the Federal Register. A copy of the 'Routine Uses' is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.</p>			
I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me (or of the above-name individual if the individual is legally unable to give consent) by (specify the name of the VA facility, newspaper, magazine, television station, etc.)			
->During an interview conducted at the VA Ann Arbor Health System for the purposes of a research study.			
While I am (describe the activity, if any to be photographed or recorded)			
-> Participating in a research study and doing a one-on-one interview.			
I authorize disclosure of the picture and/or voice recording to (specify name and address of the organization, agency, or individual(s) to whom the release is to be made)			
->Researchers at the VA Ann Arbor Health System only.			
I understand that the said picture, video and/or voice recording is intended for the following purpose(s):			
->So that researchers can carefully review the interview and learn about my personal experiences. My voice recording will be transcribed into a text document.			
I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.			
SIGNATURE OF INDIVIDUAL OR OTHER LEGALLY AUTHORIZED PERSON ->		DATE ->	
PERMISSION OBTAINED BY (NAME - TITLE - ADDRESS) ->			
SIGNATURE OF INTERVIEWER OR INDIVIDUAL OBTAINING CONSENT ->		DATE ->	
PRODUCTION TITLE ->		PRODUCTION NUMBER ->	
INDIVIDUAL' S NAME AND ADDRESS		IMPORTANT: This form must always be completed prior to the making or using pictures, video or voice recording(s) of any VA patient. If any patient health or demographic information is to be provided or released with the picture, video or voice recording, VA Form 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.	

VA FORM 10-3203  
MAY 2005



# Department of Veterans Affairs Research Consent Form

**VA AAHS Research IRB**

Approved 1/09/14

Expires 1/08/15

**Title of Study:**

Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: CAREGIVERS

**Principal Investigator:**

Lisa DiPonio

**VAMC:** VA Ann Arbor

Healthcare System

**PURPOSE OF RESEARCH STUDY:**

We are conducting a study about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. The study is asking caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction.

**DESCRIPTION:**

This study is sponsored by the U.S. Department of Defense and being done in collaboration with the University of Michigan. People who are between the ages of 18 and 70 and are able to communicate comfortably in English and have been a caregiver of someone with a spinal cord injury for at least 30 days are eligible for this study. You must be able to travel to the VA to participate in the interview. You were identified as a caregiver either by a veteran with SCI that you care for or you learned about this study from a flyer or work of mouth. Ten caregivers of someone with an SCI will participate in this study.

In this study, you will complete a one-on-one interview about your personal experience as a caregiver of someone with an SCI. The interview will cover topics like how bowel and bladder problems affect things like quality of life, independence and community participation. The interview will take place in a private room at the Ann Arbor VA and will take about 60 to 90 minutes.

The one-on-one interviews will be audio-recorded and then transcribed into a document. This is because the researchers will carefully go over what you talked about to learn more about bowel and bladder and quality of life.

After your interview, if you agree, we may call you again to see if you are interested in participating in a focus group to talk more about the things you told us in your interview. Not everyone will be invited to be in the focus group. If we do invite you, we will call you back within a month after your one-on-one interview. The focus group will take place at the University of Michigan. For the focus group, about 10 other caregivers of someone with an SCI will meet to talk about their experience, led by a group facilitator. If you are interested, we will give you contact information for the UM study team and you can call them to learn more about the study. If you agree to be in the focus group, you will sign a different consent form from the University of Michigan.

**Please check one of the boxes below to tell us whether it is OK to see if you are interested in learning more about a focus group.**

- ☐ Yes, it is OK to call me  
☐ No, please do not call me

**RISKS:**

The risks of participating in this study are very minimal. There is a risk of a loss of confidentiality of your research records. Some questions during the interview may make you uncomfortable. You may choose not to answer any question or stop the interview at any time with no penalty to you. There may be other risks that are unforeseeable at this time. Your decision whether or not to participate in this study and anything you tell us will

**RESEARCH SUBJECT IDENTIFICATION: (Required information)**

				/ /
Last Name	First Name	Mid. Init.	Last-4 SSN	Date (mm/dd/yy)

# Department of Veterans Affairs Research Consent Form

**VA AAHS Research IRB**

Approved 1/09/14

Expires 1/08/15



**Title of Study:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: CAREGIVERS

**Principal Investigator:** Lisa DiPonio

**VAMC:** VA Ann Arbor  
Healthcare System

not be shared with anyone outside the study team. If you are a caregiver of a veteran with an SCI who is also in the study, nothing you tell us will be shared with the veteran. It is up to you whether you want to tell the person you care for if you joined the study.

## **BENEFITS:**

You are not likely to directly benefit from participating in this study. On the other hand, other people with SCI may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life.

## **ALTERNATE COURSES OF ACTION:**

This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way and you will not lose any benefits that you may be entitled to. If you choose to end the study early, you may freely do so with no

## **STATEMENT OF RESEARCH RESULTS:**

To protect your privacy and confidentiality, during the interviews we will ask that as much as possible, you don't use your name to say anything that identifies who you are, like where you live. But just to be sure, the person who transcribes the interview will remove anything you may have said that identifies you. Finally, we will read each transcript carefully to make sure nothing was missed that may identify you. For any study data, like a form or the transcription of your interview, your name will be connected to an anonymous study number that will be on the study paperwork. The link between your name and that number will be kept separate from the study forms. Nothing you tell us during the interview will be shared with any person outside the researchers or any other study participant.

This study is taking place in collaboration with the University of Michigan which is the lead center. Once your interview has been transcribed into a document it will be sent to the University of Michigan; the audio recording if your interview will NOT be sent. That recording will stay at the VA. We will send the document electronically using a secure, password protected website that only the study team can access. The document will not contain any information that will identify who you are. Instead it will have an anonymous code number and the link between your name and that code number will stay at the VA on a protected electronic file.

Researchers at the University of Michigan will protect your data by storing it on a password-protected server at the University of Michigan and only the researchers will be able to open it. Eventually, your data will be combined with everyone who is in this study and like you, they will all have codes to keep their information confidential.

If results of this study are reported in medical journals or at meetings, you will not be identified by name, by recognizable photograph, or by any other means without your specific consent. No information by which you can be identified will be released or published unless required by law. We will let you and your physician know of any important discoveries made during this study which may affect you, your condition, or your willingness to participate in this study.

## **SPECIAL CIRCUMSTANCES:**

There will be not be any costs to you for any additional care that you receive as a participant in this research study.



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**Title of Study:**

Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after Spinal Cord Injury: CAREGIVERS

**Principal Investigator:**

Lisa DiPonio

**VAMC:** VA Ann Arbor  
Healthcare System

**COMPENSATION:**

When the interview is completed, you will receive a \$25 check in the mail as thanks for your time and willingness to share you experience in this study. The University of Michigan accounting department which will process your payment will need your name and address. This information will be given directly to the accounting department by the study coordinator. And it will not be associated with your study information in any way. You may decline compensation if you do not want to share this information with the University of Michigan accounting department.

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**Principal Investigator:**

Lisa DiPonio

**VAMC:** VA Ann Arbor  
Healthcare System**RESEARCH SUBJECT'S RIGHTS:**

\_\_\_\_\_ has explained this research study and answered all questions. The risks or discomforts and possible benefits of the study have been described. Other choices of available treatment have been explained. Some veterans are required to pay co-payments for medical care and services provided by VA. These co-payment requirements will continue to apply for VA care and services that are not part of this study.

Participation in this study is entirely voluntary. You may refuse to participate. Refusal to participate will involve no penalty or loss of rights to which individuals are entitled. Participants may withdraw from this study at any time without penalty or loss of VA or other benefits. In the event that you sustain an injury or illness as a result of your participation in this VA approved research study, all necessary medical treatment (except in limited circumstances), will be provided in a VA medical facility. You will be treated for the injury at no cost to you. However, no additional compensation has been set aside. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

In case there are medical problems, an injury, or if you have questions, concerns or complaints about the research study, you can contact member(s) of the research study team: Edward Rohn, Study Coordinator, can be called at (734) 763-6189 during the day and Lisa DiPonio, MD can be contacted after hours at (734) 936-6266 (follow the prompts and enter Page ID# 10171).

You may contact the VA Human Studies coordinator at 734-845-3440 to ask questions about your rights as a research subject and to verify this study is reviewed and approved by the VA. You may also call when research study staff are not available or to discuss your questions or concerns with someone other than study staff. You may learn more about research at the VA Ann Arbor Healthcare System at [www.annarbor.research.va.gov](http://www.annarbor.research.va.gov)

I have been informed about my rights as a research subject, and I voluntarily consent to participate in this study. I will receive a signed copy of this consent form.

X \_\_\_\_\_  
Signature of Subject

X \_\_\_\_\_  
(Print Name)

X \_\_\_\_\_  
Date (mm/dd/yy)

X \_\_\_\_\_  
Signature of person obtaining consent  
(Study personnel must be approved by VA IRB.)

X \_\_\_\_\_  
(Print Name)

X \_\_\_\_\_  
Date (mm/dd/yy)

**IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086) MUST BE CONSECUTIVELY NUMBERED.**

## Department of Veterans Affairs HIPAA Authorization Form

<b>Title of Study:</b>	Double-click to enter study title here		
<b>Principal Investigator:</b>	Double-click to enter name of PI here	VA Ann Arbor Healthcare System	

### REQUEST FOR PATIENT AUTHORIZATION FOR ACCESS TO PROTECTED HEALTH INFORMATION

1. By signing this document, you authorize the Veterans Health Administration (VHA) to provide **Lisa DiPonio, MD** and the research team permission to view and collect the following Personally Identifying Information (PII) and Protected Health Information (PHI) about you for research purposes:  
 -> ***Your name, where you live, your telephone number and email address***
2. The research investigators will collect your PHI for the following specific research purposes (a database?):  
 -> ***The research investigators will NOT collect your PHI information.***
3. Confidentiality Statement: The confidentiality of research records that identify you as a subject will be maintained and protected as follows :-> ***Any data collected in this study will be stored separately from any information that identifies you. We will store research data in locked cabinets in locked offices and on computers that require a password that only the study team will have.***
4. You may refuse to sign this authorization and refuse to allow the disclosure of your Protected Health Information. Your refusal will not affect your ability to receive medical care or benefits at the VA Ann Arbor Healthcare System.
5. This authorization will expire at the end of the research study.
6. This authorization may be revoked at any time by sending a written request to **Lisa DiPonio, MD, 2215 Fuller Road, Ann Arbor, 48105**. If you revoke this authorization, **Lisa DiPonio, MD** and the research team can continue to use information about you that has been collected. No information will be collected after you revoke the authorization.
7. The Ann Arbor VAMC complies with the requirements of the Health Insurance Portability and Accountability Act of 1996 and its privacy regulations and all other applicable laws that protect your privacy. The research records from this study may be reviewed by the Institutional Review Board and Compliance Monitors of the Ann Arbor VAMC and by other government agencies (including, but not limited to: the Government Accounting Office, Office of Human Research Protections, VA Office of Inspector General and VA Office of Research Oversight). Individually-identifiable health information that may be disclosed under this authorization may no longer be protected by Federal laws or regulations and may be subject to re-disclosure by the recipient.
8. **You may check any of these areas of especially sensitive information that you will allow to be disclosed to the entities in the item above.**  

☐ **Alcohol abuse treatment**   
 ☐ **Drug abuse treatment**   
 ☐ **Sickle Cell Anemia**   
 ☐ **HIV infection**
9. As part of the study, we may disclose your information to the **University of Michigan** who is coordinating this study so that we can process your subject payment. We will not share any information with these persons unless they agree to keep the information confidential and use it only for the purposes related to the study.
10. As the sponsor of this research, the Department of Defense may access the research records.

X _____ Signature of Subject	[ _____ ] <b>Last 4-SSN</b>	X _____ (Print Name)	X _____ Date (mm/dd/yy)
X _____ Signature of Personal Representative <small>(A Court appointed legal guardian, or a legally authorized Power of Attorney.)</small>	<u>leave blank if N.A.</u> X _____ (Print Name)		X _____ Date (mm/dd/yy)



# Department of Veterans Affairs

<b>CONSENT FOR USE OF PICTURE AND/OR VOICE</b>		<b>CONSENT OF (Name)</b> ->
<p>NOTE: The information requested on this form is solicited under the authority of title 38, United States Code. The execution of this form does not authorize disclosure of the materials specified below except for the purpose(s) stated. The specified material may be used within the VA for authorized purposes, such as for education of VA personnel or for VA research activities. It may also be disclosed outside the VA as permitted by law. If the material is part of a VA system of records, it may be disclosed outside the VA as stated in the 'Routine Uses' in the "VA Privacy Act Systems of Records" published in the Federal Register. A copy of the 'Routine Uses' is available upon request to the administrative office of the VA facility involved. You do not have to consent to have your picture or voice taken, recorded, or used. Your refusal to grant your consent will have no effect on any VA benefits to which you may be entitled.</p>		
I hereby voluntarily and without compensation authorize pictures and/or voice recording(s) to be made of me (or of the above-name individual if the individual is legally unable to give consent) by (specify the name of the VA facility, newspaper, magazine, television station, etc.)		
-> <b>During an interview conducted at the VA Ann Arbor Health System for the purposes of a research study.</b>		
While I am (describe the activity, if any to be photographed or recorded)		
-> <b>Participating in a research study and doing a one-on-one interview.</b>		
I authorize disclosure of the picture and/or voice recording to (specify name and address of the organization, agency, or individual(s) to whom the release is to be made)		
-> <b>Researchers at the VA Ann Arbor Health System only.</b>		
I understand that the said picture, video and/or voice recording is intended for the following purpose(s):		
-> <b>So that researchers can carefully review the interview and learn about my personal experiences. My voice recording will be transcribed into a document.</b>		
I have read and understand the foregoing and I consent to the use of my picture and/or voice as specified for the above-described purpose(s). I further understand that no royalty, fee or other compensation of any character shall become payable to me by the United States for such use. I understand that consent to use my picture, video and/or voice recording is voluntary and my refusal to grant consent will have no effect on any VA benefits to which I may be entitled. I further understand that I may at any time exercise the right to cease being filmed, photographed or recorded, and may rescind my consent for up to a reasonable time before the picture, video or voice recording is used.		
<b>SIGNATURE OF INDIVIDUAL OR OTHER LEGALLY AUTHORIZED PERSON</b> ->		<b>DATE</b> ->
<b>PERMISSION OBTAINED BY (NAME - TITLE - ADDRESS)</b> ->		
<b>SIGNATURE OF INTERVIEWER OR INDIVIDUAL OBTAINING CONSENT</b> ->		<b>DATE</b> ->
<b>PRODUCTION TITLE</b> ->		<b>PRODUCTION NUMBER</b> ->
<b>INDIVIDUAL'S NAME AND ADDRESS</b>		<b>IMPORTANT:</b> This form must always be completed prior to the making or using pictures, video or voice recording(s) of any VA patient. If any patient health or demographic information is to be provided or released with the picture, video or voice recording, VA Form 10-5345, Request for and Authorization to Release Medical Records or Health Information is required prior to the release of such data to any source.

**VA FORM 10-3203**  
**MAY 2005**

# Obtaining Informed Consent Checklist RCO 2/28/13

>Document to be completed for each consent obtained and filed with the original informed consent document<

RESEARCH STUDY IDENTIFICATION (Required information)
STUDY TITLE: <u>Psychological &amp; Behavioral Factors Associated with Bowel &amp; Bladder Management after SCI</u>
PI: <u>Lisa DiPonio, MD</u>
NAME OF STUDY TEAM MEMBER OBTAINING CONSENT: _____
ROLE OF STUDY TEAM MEMBER OBTAINING CONSENT: _____

RESEARCH SUBJECT IDENTIFICATION: (Required information)				
				/ /
<b>Last Name</b>	<b>First Name</b>	<b>Mid. Init.</b>	<b>Last-4 SSN</b>	<b>Date (mm/dd/yy)</b>

A.	<< Date ALL required SIGNATURES (Subject, Witness (If required by IRB) and Person Obtaining Consent), their PRINTED NAMES and the DATES they signed the informed consent document (ICD) have been checked and appear in the proper location
B.	<< Date and Time of Day (ICD) was reviewed and deemed complete and valid
C.	<< Date and Time of the subject's first study activity or involvement
	Verify and Initial each of the following 12 requirements.
1.	Informed consent [and HIPAA Authorization, if required by VA-IRB] was obtained from this subject prior to study participation. Note: Recorded Date and Time of Day (ICD) was reviewed and deemed complete and valid (B.) MUST be prior to recorded Date and Time of Day Subject began study participation (C).
2.	A VA Scope of Practice Form has been signed by the PI and approved by the VA IRB which designates me as an authorized agent of the PI and qualified to obtain consent for this study.
3.	This prospective subject was given adequate time necessary to carefully and fully read the Informed consent document (ICD) and all questions were answered to his/her satisfaction.
4.	All aspects of this subject's study involvement, including the purpose of the study, known and potential risks, possible benefits and alternatives to study participation were explained and discussed prior to subject signing the ICD.
5. N/A	If required, an enrollment note and scanned Consent Form image will be entered in the patient's electronic medical record (CPRS).
6.	Subject has been consented using the most recently approved, VA logo date-stamped version of VA Form 10-1086.
7.	A copy of the fully-completed signed, original informed consent document has been issued to this subject and he/she was instructed to retain that copy for reference and to ask any and all questions that might arise throughout his/her study involvement.
8.	The subject has been shown where in the ICD to locate study team phone number(s) and the phone number of the VAAHS IRB Coordinator. The subject has been reminded to call with any questions or concerns. Doug Feldman @ 734.845.3440
9.	The subject has been informed that participation is entirely voluntary and that they may withdraw their participation at any time and for any reason.
10.	I'm aware that original ICDs and all copies must be printed and issued as single-sided documents and that the original signed ICD must be kept in the investigator's project files on VA property.
11.	It is my opinion (person obtaining consent) and the opinion of the Principal Investigator that this subject is capable of understanding the informed consent document and what his/her overall involvement in the study will entail.
12.	I know I can contact the VAAHS IRB Coordinator at 734.845.3440 or the Research Compliance Officer at 734.845.3766 if I have questions or concerns regarding the consent of this or any individual considering study participation.

## UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

### NAME OF STUDY AND RESEARCHERS

**Title of Project:** Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI

**Principal Investigator:** Denise G. Tate, PhD, ABPP

**Co-Investigators:** Lisa DiPonio, M.D., Anne Pelletier-Cameron, MD, Gianna Rodriguez, MD, Randy Roth, PhD, Claire Kalpakjian, PhD, and Martin Forchheimer, MPP

### GENERAL INFORMATION

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affect quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. This study is funded by the U.S. Department of Defense. The study is asking persons with spinal cord injury (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder dysfunction. To learn more about these, we are asking people with spinal cord injury and caregivers to be involved in a focus group session.

A total of 20 people (10 people with spinal cord injury and 10 caregivers of someone with a spinal cord injury) will participate in this research study. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study. Caregivers of someone with a spinal cord injury will have worked with someone with SCI for at least 30 days to be eligible and can be a family member or non-family member.

The study will involve a **focus group** and last 60 – 90 minutes. There will be two *separate* focus groups – one for people with spinal cord injury and one for caregivers. For the people with spinal cord injury, the discussion will be about the kinds of problems people with spinal cord injury experience with bowel and bladder problems, how it affects their independence, coping with problems, or how taking care of bowel and bladder functions affect relationships. For caregivers, the discussion will be about the experience of helping to managing bowel and bladder problems and its effect on relationships. The focus group discussions will be **audio-recorded**. This is because the researchers will carefully go over what participants talked about to learn more about bowel and bladder and quality of life.

The **risks** in this study are related to **privacy** and **confidentiality**. During the focus group, you will be talking about personal things in front of people you may or may not have met before. You are free to not say anything during any part of the discussion if you feel uncomfortable. During the discussion, we will ask you not to use your real name, but you will use a color or number to identify yourself for the audio-recording. When the recording is transcribed into a document, the researchers will carefully check to make sure there is nothing in the document that will identify you. Your name will also not be on any research paperwork. Instead, your name will be connected to an anonymous study number that will be on the paperwork. As the sponsor of this research, the Department of Defense may access the research records.

There are **no direct benefits** to you for taking part in this study. On the other hand, other people with spinal cord injury may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life. This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way. There is no charge to you or your health insurance for being in this study. You will receive \$25 after participating in the focus group. The University of Michigan accounting department will need your name, address, and payment amount for tax reporting purposes.

Your signature in the next section means that you have received copies of all of the following documents:

- ☐ This "Consent to be Part of a Research Study" document. (Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)

### CONTACT INFORMATION

To find out more about the study, ask a question or express a concern about the study or if you feel you have experienced any harm from the study contact one of the following:

Principal Investigator: Denise Tate, Ph.D.

Study Coordinators: Andrea Nevedal, Ph.D., Edward Rohn, MA, Connie Pines and Sunny Roller, M.S.  
Mailing Address: 300 N. Ingalls, NI209, Ann Arbor, MI 48109-5491

Telephone:

Email:

University of Michigan Compliance Help Line at 1-888-296-2481 or if you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-888-296-2481

University of Michigan Medical School Institutional Review Board (IRBMED)  
2800 Plymouth Road  
Building 520, Room 3214G  
Ann Arbor, MI 48109-2800

## SIGNATURES

### Research Subject:

*I understand the information printed on this form. My questions so far have been answered.*

Signature of Subject: \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_

Patient ID: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

### Legal Representative (if applicable):

Signature of Person Legally  
Authorized to Give Consent \_\_\_\_\_ Date: \_\_\_\_\_

Name (Print legal name): \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Check Relationship to Subject:

☐ Parent ☐ Spouse ☐ Child ☐ Sibling ☐ Legal Guardian ☐ Other: \_\_\_\_\_

*If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.*

Reason subject is unable to sign for self: \_\_\_\_\_  
\_\_\_\_\_



## Oral Consent Elements

Read over the phone (with waiver of documentation)

### For Focus Groups

Revised April 17, 2013

**Subject Name:** \_\_\_\_\_

**Date provided to subject:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_

We are conducting research about how neurogenic bladder and bowel in people with spinal cord injury affects health, quality of life and other things like mood, going out into the community and taking care of bowel and bladder dysfunction. This study is funded by the U.S. Department of Defense. The study is asking people with SCI (civilians and veterans) and caregivers of someone with spinal cord injury about their experiences in managing bowel and bladder and the associated problems.

To learn more about these, we are asking people with spinal cord injury and caregivers to be involved in a one-on-one interview, a focus group session and for those participants with SCI, to complete questionnaires.

A total of 20 people (10 people with spinal cord injury and 10 caregivers of someone with a spinal cord injury) will participate in this research study. People who are between the ages of 18 and 70 and are able to communicate comfortably in English are eligible for this study.

### FOR SCI ONLY

People with a spinal cord injury will have had their SCI during the last 12 months or be 10 or more years post-injury.

The study will involve a **focus group** and last 60 – 90 minutes. There will be two *separate* focus groups – one for people with spinal cord injury and one for caregivers. For the people with spinal cord injury, the discussion will be about the kinds of problems people with spinal cord injury experience with bowel and bladder problems, how it affects their independence, coping with problems, or how taking care of bowel and bladder functions affect relationships. For caregivers, the discussion will be about the experience of helping to managing bowel and bladder problems and its effect on relationships. The focus group discussions will be **audio-recorded**. This is because the researchers will carefully go over what participants talked about to learn more about bowel and bladder and quality of life.

**(HIPAA Authorization if participating ONLY in the focus group; if they have participated in the one-on-one interview, do NOT read this)**

We will also need to review your medical record to find out more about your spinal cord injury treatment related to bowel and bladder care. There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- The Department of Defense may request to see information about you as part of this study.

- Study sponsors or funders, or safety monitors or committees, may need the information to, make sure the study is done safely and properly, or analyze the results of the study.
- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, payment amount, and related information for tax reporting purposes.

#### FOR CAREGIVERS ONLY

Caregivers of someone with a spinal cord injury will have worked with someone for at least 30 days to be eligible. They can be a family member or non-family members.

The study will involve a **focus group** and last 60 – 90 minutes. There will be two *separate* focus groups – one for people with spinal cord injury and one for caregivers. For the people with spinal cord injury, the discussion will be about the kinds of problems people with spinal cord injury experience with bowel and bladder problems, how it affects their independence, coping with problems, or how taking care of bowel and bladder functions affect relationships. For caregivers, the discussion will be about the experience of helping to managing bowel and bladder problems and its effect on relationships. The focus group discussions will be **audio-recorded**. This is because the researchers will carefully go over what participants talked about to learn more about bowel and bladder and quality of life.

#### FOR BOTH GROUPS

The **risks** in this study are related to **privacy** and **confidentiality**. During the focus group, you will be talking about personal things in front of people you may or may not have met before. You are free to not say anything during any part of the discussion if you feel uncomfortable. During the discussion, we will ask you not to use your real name, but you will use a color or number to identify yourself for the audio-recording. When the recording is transcribed into a document, the researchers will carefully check to make sure there is nothing in the document that will identify you. Your name will also not be on any research paperwork. Instead, your name will be connected to an anonymous study number that will be on the paperwork.

There are **no direct benefits** to you for taking part in this study. On the other hand, other people with spinal cord injury may benefit by the information we learn in terms of how to optimize treatments and reduce negative impacts on quality of life. This research is voluntary. You do not have to take part in this study. Choosing not to be in this research study will not affect your care in any way. There is no charge to you or your health insurance for being in this study. You will receive \$25 after participating in the focus group. The University of Michigan accounting department will need your name, address, and payment amount for tax reporting purposes.

Participant consents to join the study                      **Yes**    **No**

Interviewer signature and date: \_\_\_\_\_

Interview Date	/ /
Participant ID	
Interviewer	

## PERSON WITH SCI INTERVIEW GUIDE

**INTRODUCTION:** Thank you for participating in our study. We are interested in learning about your perspective and your experiences of what it's like to have to manage your bowel and bladder. We would like for you to be as honest as you can and share your true feelings. We hope that by learning about your experiences and perspectives we can learn about what it's like to live with the loss of bladder and bowel control and try help others in the future. Everything you share with me will be confidential. If you need to take a break or are feeling tired please let me know and we can stop the interview. Do you have any questions before we get started with the interview? If it is OK with you I would like to turn on the audio recorder. Feel free to ask questions as we go along and share additional information that you think might be helpful for us to know about your experiences.

**GUIDING CONCEPT FOR INTERVIEWERS:** How has the management of and complications around bowel and bladder issues impacted the PWSCI's quality of life?

How has your care of your bowel and bladder affected your QOL? How has it affected the way you live your life?

**SECTION 1: BACKGROUND INFORMATION:** Before we get started with the main part of the interview I would like to learn more about you.

- 1) Please tell me a little bit about yourself and the circumstances surrounding your injury.
- 2) We find the stories people tell are a valuable way to understand people's life experiences. Please tell me your story of living with the loss of bladder and bowel function.

Probes (use if they struggle with the question):

- What is important to understand about your bladder and bowel function?
- What was it like when you realized you had bladder and bowel dysfunction?
- What were some of the biggest changes in your life when you were injured?

**SECTION 2: BLADDER AND BOWEL PROGRAM:** Now that we've had a few minutes to talk I would like to know more about your experiences with having to manage your bladder and bowel.

**GENERAL ROUTINE**

1) Please describe your daily routine related to managing bladder and bowel for me.

Consider these follow-up probes for specific parts of the day/routine
Morning Routine
Afternoon Routine
Evening Routine
Bedtime Routine

2) When you leave the house (e.g., work, shopping, appointments, social events, etc), what kinds of things do you do to prepare for the trip related to bladder and bowel care?

- Do you have strategies or have to plan ahead?
- Have you had accidents or unexpected things happen?
- To what extent is being away from home difficult/problematic? Or easy?

3) To what extent has your program changed since you've been living with a spinal cord injury? [consider that people with long-term SCI might have had more changes]

**INTERVIEWER:** Be aware of time and redundancy; skip Section 3 if necessary.

**SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS:** The next few questions ask about challenges, problems and complications that you may have experienced related to managing your bladder and bowels.

1) What were some of the difficulties you've experienced since having to manage your bladder and bowels?

- Probes: accidents, finding proper facilities, etc.

2) What are some of the strategies you've used to deal with/resolve these difficulties?

**COMPLICATIONS:** For the next few questions we are interested in learning about medical complications and health issues you may have experienced related to bladder and bowel.

1) What kind of complications have you had related to your bladder?

- Health complications: UTIs, bladder/kidney stones, incontinence, leakage, sores from cathing, pain)
- Other complications

2) What kind of complications have you had related to your bowels?

- Health complications: hemorrhoids, constipation, incontinence, bloating, stomach pain, skin infection/sores.
- Other complications

3) What aspects continue to be a problem/concern for you?

4) What have you found helps you to avoid complications?

**CAREGIVER/ATTENDANT RELATIONSHIP:** For this next section we are interested in learning about your relationship with your caregiver. [If No caregiver, then skip these questions]

1) Do you prefer the term "caregiver" or "personal attendant/assistant"?

2) In what ways does your caregiver(s) help you manage your bladder?

3) In what ways does your caregiver(s) help you manage your bowels?

4) How do you feel about the care you receive?

- Any challenges to having someone help you with your bowel and bladder?
- What concerns, if any, do you have about the quality of the care you receive? (e.g., abuse, independence, proper care, impact complications, create challenges, helpful, provide assistance when needed)

5) How do you feel about your relationship/experience with your caregiver?

**RELATIONSHIP WITH DOCTOR/HEALTH CARE PROVIDERS:** This section is about your experiences with your doctor/nurse or other health care professionals that you may see for bladder and bowel care or treatment.

1) Refresh my mind – do you see the same person for bladder and bowel care? Or do you see separate health providers?

2) What do they suggest you do for bladder care?

- What do you think about these recommendations? Why or why not?
- Are they realistic for you to follow or for your situation?
- Are you able to talk to them about your concerns, questions, or modifying the program? Why or why not?

3) What do they suggest you do for bowel care?

- What do you think about these recommendations? Why or why not?
- Are they realistic for you to follow or for your situation?
- Are you able to talk to them about your concerns, questions, or modifying the program? Why or why not?

#### **SECTION 4: SOCIAL CONSEQUENCES OF LOSS OF BLADDER AND BOWEL**

**CONTROL:** Now that we've had a chance to talk about your management routine and bladder and bowel program - I would like to learn more about how living with the loss of bladder and bowel control and how your program impacts the social aspects of your life such as relationships with other people, going out, living the life you want to live.

#### **GENERAL RELATIONSHIPS**

1) In general, to what extent has the loss of bladder and bowel control has impacted relationships with the people around you?

2) To what extent does it impact your ability to open up to others about your condition?

3) Do other people know that you experience the loss of bladder and bowel control? Why or why not?

**INTIMATE/SEXUAL RELATIONSHIPS:** A lot of people with SCI have mentioned that intimacy and sexuality are very important but can be challenging while living with bladder and bowel dysfunction

1) How important is sexuality and intimacy to you?

2) Have you dated or been in a relationship since your injury?

- If Yes – are you currently dating or in a relationship?
- If No – why not?

3) Can you tell me how bowel and bladder dysfunction impacts your ability to have intimate and sexual relationships?

- Probe: challenges, engage in relationship, find suitable partner
- How have you worked around or dealt with any of these issues?

4) To what extent and in what ways has bladder and bowel dysfunction impacted your physical sexual functioning?

- Probe: dexterity, lack of function, lack of sensation, body positioning
- How have you worked around or dealt with any of these issues?

5) To what extent and in what ways does neurogenic bladder and bowel impact your ability to be intimate/romantic

- Probe: fear of opening up to someone, finding a partner, dating, accidents during sexual activity, privacy
- How have you worked around or dealt with any of these issues?

### **FAMILY/FRIENDS - INFORMAL RELATIONSHIPS**

1) To what extent has loss of bladder and bowel control impacted relationships with family or household members?

2) To what extent has loss of bladder and bowel control impacted friendships?

### **COMMUNITY BASED – FORMAL RELATIONSHIPS**

1) How does living with the loss of bladder and bowel function impact your ability to have professional, work, community relationships?

2) To what extent has loss of bladder and bowel control impacted your ability to participate in community, social or work related activities? (e.g., work, leisure activities, church, hobbies, volunteering)?

- 3) Are there any activities (related to home or community life) that you would like to participate in that you do not do now? If so, please describe the barriers or challenges that you feel prevent you from participation. How do you work around these issues?

## LIFE COURSE EXPECTATIONS

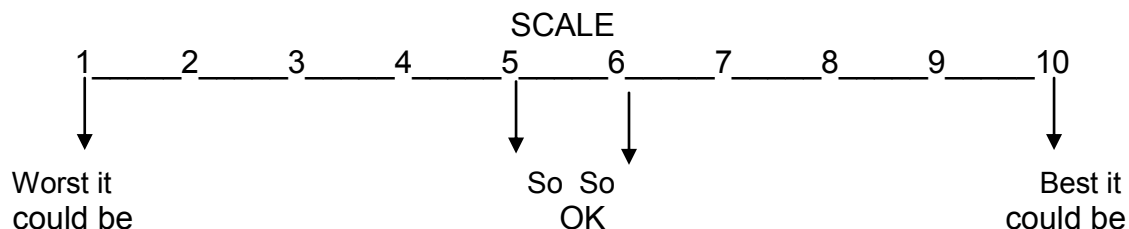
- 1) **PRESENT:** To what extent does living with bladder and bowel dysfunction impact your life goals and life expectations (e.g., how you thought you would live your life or how you want to live your life)?

- Your ability to fulfill the roles that are important to you? (work, family relationships, spouse/partner/parent, social relationships, being independent)
- How have you worked around or dealt with any of these issues?

- 2) **FUTURE:** In terms of your future goals (hopes and aspirations) what do you hope to be doing, five years down the road?
- 3) To what extent has living with bladder and bowel impacted your sense of self?

## QUALITY OF LIFE/LIFE SATISFACTION

- 1) This set of questions has to do with your life *right now* and how satisfied you are with the way your life is going. [SHOW SCALE] On a scale from 1-10 with 1 meaning “worst it could be” and 10 meaning “best it could be” and the middle numbers (5-6) meaning “so-so” or “OK”.



- 2) Can you tell me why you picked that number? [Probe for details].

- What areas of your life do you find most satisfying or enjoyable? Least satisfying or enjoyable?
- What areas or aspects pertaining to quality of life (whether good or bad) are most important to you, right now?
- [if not mentioned] How big an impact does bowel dysfunction have on your quality of life? What about bladder dysfunction? Please describe.



## **FINAL THOUGHTS**

- 1) What advice would you give someone else who experiences bladder and bowel complications?
- 2) Is there anything you wish you had known sooner?
- 3) IF THE SUBJECT SEEMS TO HAVE ADJUSTED WELL:
  - a. You seem to have adjusted well to living with neurogenic bladder and bowel. What would say has been the secret to your success?
  - b. Is there anything about you as a person that has helped you through all this?
- 4) IF THE SUBJECT HAS HAD DIFFICULTY ADJUSTING:
  - a. You've gone through so much; do you see a way for things to improve in the future?
  - b. What if anything, would improve the quality of your life?
  - c. Do you feel your life will be different in five years? Why or why not?
- 5) Thank you for talking with me and sharing your perspective. Is there anything else that we haven't already talked about today that will help me understand your experiences with neurogenic bladder and bowel?
- 6) IF THEY HAVE A CAREGIVER/PERSONAL ATTENDANT:
  - a. Do you think your caregiver/personal attendant would be willing to sit down with us for a similar interview?
  - b. NOTE: If "yes", turn off tape recorder and collect contact information for the caregiver.

<b>Completion Date</b>	/ /
<b>Participant ID</b>	
<b>Interviewer</b>	

## **MEASURES PACKET**

Please be honest and thorough as possible. Someone from our staff will contact you soon to schedule an interview to complete these questions. The interview can be in person or by phone. It must be completed within two weeks of completing the face-to-face interview. Please review these items prior to that meeting.

**Thank you for being part of our study!**

## Personal Characteristics Form – Subjects with SCI

Gender: ☐ Male ☐ Female

Race: ☐ Caucasian ☐ African American ☐ Asian ☐ Other \_\_\_\_\_

Ethnicity: ☐ Not Hispanic ☐ Hispanic

Date of Injury: \_\_\_\_\_

Age at Injury: \_\_\_\_\_

Current Age: \_\_\_\_\_

Etiology of SCI: ☐ Vehicular ☐ Sports ☐ Fall ☐ Violence ☐ Other \_\_\_\_\_

Have You Served in the U.S. Military? ☐ Yes ☐ No

Marital Status Currently

☐ Single, Never Married ☐ Married ☐ Significant Other ☐ Divorced  
☐ Separated ☐ Widowed

Marital Status at Injury

☐ Single, Never Married ☐ Married ☐ Significant Other ☐ Divorced  
☐ Separated ☐ Widowed

Current Vocational Status (Check all that apply, place an X in primary category):

☐ Employed ☐ Homemaker ☐ Student ☐ Unemployed ☐ Retired - Age  
☐ Retired – Disability ☐ Other \_\_\_\_\_

Vocational Status at Injury (Check all that apply, place an X in primary category):

☐ Employed ☐ Homemaker ☐ Student ☐ Unemployed ☐ Retired  
☐ Other \_\_\_\_\_

Highest Level of Education Completed

☐ 8<sup>th</sup> grade or less ☐ 9<sup>th</sup>-11<sup>th</sup> grade ☐ High School or GED ☐ Associates Degree  
☐ Bachelor's Degree ☐ Master's Degree ☐ Doctorate ☐ Other \_\_\_\_\_

Living Situation (Select all that apply)

☐ Live Alone ☐ Live with Spouse/SO ☐ Live with Parents ☐ Live with Children  
☐ Live with Paid Caregiver ☐ Live with Roommates ☐ Live with Other \_\_\_\_\_

If Living with Children (Number)

☐ 0 – 4 years old ☐ 5-18 years old ☐ Adult

Nature of Spinal Cord Injury

☐ Incomplete Paraplegia    ☐ Complete Paraplegia  
☐ Incomplete Tetraplegia    ☐ Complete Tetraplegia

Household Income (from all sources)

☐ < \$25,000    ☐ \$25,000 - \$49,999    ☐ \$50,000 - \$74,999    ☐ > \$80,000

Primary Payer for Health Care

☐ Auto No-Fault    ☐ Other Private    ☐ Workers' Compensation    ☐ Medicare  
☐ Medicaid    ☐ Veterans Administration    ☐ Self Pay    ☐ Other \_\_\_\_\_

What is Your Primary Source of Transportation?

☐ Car - Yours    ☐ Car – Someone Else's    ☐ Public Transportation  
☐ Other \_\_\_\_\_

Do You Have a Caregiver Who Assists you with Bowel and/or Bladder Management?

☐ Yes    ☐ No

**Spinal Cord Injury Bowel and Bladder Treatment Index LT 1 Year Short Form\***

Date of Data Collection: MMDDYYYY \_\_\_\_\_

Site of data collection: Clinic \_\_\_\_ Phone \_\_\_\_ Other \_\_\_\_\_

Subject Identification Code: \_\_\_\_\_ Data Collector Initials: \_\_\_\_\_

Instructions to the subject: This questionnaire asks about your methods of bowel and bladder management, complications and related health and well-being issues. It includes questions about the medications that you take, symptoms and complications you may have experienced and other related issues. Let me know if you have any questions. Please note that the time of reference is not the same for all of the questions. Also, for some questions, more than one answer may be applicable.

**BOWEL**

**A. Bowel Management Methods**

- 1. What have been your methods of defecation and bowel care during the last 4 weeks? If you use more than one method, classify the method that you use most often as your main method and the others as supplementary methods. If you always use two methods, classify both as main methods.**

	Main*	Supplementary*
Normal Defecation (require no special procedures or devices)	<input type="checkbox"/>	<input type="checkbox"/>
Straining/ bearing down to empty	<input type="checkbox"/>	<input type="checkbox"/>
Digital ano-rectal stimulation ( <u>circular stimulation of the anal canal &amp; rectum w/ finger to assist with bowel evacuation</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Rectal Suppositories	<input type="checkbox"/>	<input type="checkbox"/>
Digital evacuation ( <u>using finger to help remove stools</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Enema (> 150 mL)	<input type="checkbox"/>	<input type="checkbox"/>
Other Flushing, e.g., Peristeen™ ( <u>using warm water from a tube placed in the rectum to stimulate the colon to release stool</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Colostomy ( <u>always a main method</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Electrical Implant to Stimulate Bowel Function	<input type="checkbox"/>	<input type="checkbox"/>
Oral laxatives / Medications	<input type="checkbox"/>	<input type="checkbox"/>
Other method _____	<input type="checkbox"/>	<input type="checkbox"/>

- 2. Has your method of bowel management changed during since your initial discharge from rehabilitation?**

☐ No ☐ Yes Please explain: \_\_\_\_\_

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

**3. Since your initial discharge from rehabilitation, how independent have you been with your bowel management routine?\***

- ☐ Require total assistance      ☐ Require partial assistance; does not clean self  
☐ Require some assistance; clean self independently  
☐ Use toilet independently but need adaptive devices or special setting (e.g. bars)  
☐ Use toilet independently

**4. What was the average number of hours per day that you spent on bowel management activities during the last 4 weeks? \_\_\_\_\_ Hours per day**

**B. Complications and Symptoms**

**5. Have you ever been bothered by any of these problems since your initial discharge from rehabilitation?\***

- ☐ Hemorrhoids      ☐ Sores around the anus      ☐ Fissures (a crack inside the anus)  
☐ Rectal Abscess (pus collects in the anal/rectal area)  
☐ Rectal prolapse (the inside of the rectum turns inside out and comes out of the anus)  
☐ Anal skin problems      ☐ Other \_\_\_\_\_

**6. Do you have chronic constipation? ☐ No      ☐ Yes**

**7. Since your initial discharge from rehabilitation, how often have you had incontinence resulting in either liquid or solid stools?\***

- ☐ Two or more times daily      ☐ Daily  
☐ Not every day but at least once per week  
☐ Not every week but at least once per month      ☐ Less than once per month  
☐ Never      ☐ Not Applicable

**C. Satisfaction and Lifestyle**

**9. How big of an impact does bowel dysfunction have on your quality of life?\***

- ☐ Major Impact      ☐ Some Impact      ☐ Little Impact      ☐ No Impact

**10. How satisfied are you with your bowel management routine?\*\***

- ☐ Very Satisfied      ☐ Satisfied      ☐ Dissatisfied      ☐ Very Dissatisfied

**11. How flexible is your bowel management routine?\*\* (Only read response choices if subjects ask for clarification of terms)**

- ☐ Very flexible (I often change the time or frequency at which I manage my bowels.)  
☐ Quite flexible (I can delay management or alter the timing if I want to.)  
☐ Not very flexible (I don't usually change my routine unless it is unavoidable.)  
☐ Not flexible at all (I will not go to activities if they clash with my bowel management time.)

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

## BLADDER

**Instructions:** The following questions concern how you manage your bladder since your SCI. Please let me know if you have any questions as you answer them.

### 1. Are you aware of the need to empty your bladder?\*

☐ No      ☐ Yes      ☐ Not applicable

### A. Bladder Management Methods

### 2. What have been your methods of bladder voiding and bladder care during the last 4 weeks? If you use more than one method, classify the method that you use the most as your main method and others as supplementary ones. If you always use two methods, classify them both as main methods and any others as supplementary ones.\*

	Main	Supplementary
A. Normal Voiding (voluntary initiation of urination w/o reflex stimulation or compression of the bladder)	<input type="checkbox"/>	<input type="checkbox"/>
B. Bladder reflex triggering		
Voluntary (tapping on bladder area, stretching to facilitate drainage)	<input type="checkbox"/>	<input type="checkbox"/>
Involuntary (incontinent using a diaper or condom cath; not aware of voiding)	<input type="checkbox"/>	<input type="checkbox"/>
C. Bladder expression		
Straining (abdominal straining, Valsalva's manoeuvre)	<input type="checkbox"/>	<input type="checkbox"/>
External compression (Credé manoeuvre manual pressure on the lower abdominal wall)	<input type="checkbox"/>	<input type="checkbox"/>
D. Intermittent catheterization (periodically inserting a cath from the urethra to the bladder to allow urine to drain)		
Self-catheterization	<input type="checkbox"/>	<input type="checkbox"/>
Catheterization by attendant	<input type="checkbox"/>	<input type="checkbox"/>
E. Indwelling catheter (catheter is housed inside the body)		
Transurethral (IC is attached to a collection bag and stays in the bladder all of the time changed weekly or less, eg, Foley. Some patients leave IC in at night and self-cath during the day)	<input type="checkbox"/>	<input type="checkbox"/>
Suprapubic (surgically placed, inserted through the abdomen)	<input type="checkbox"/>	<input type="checkbox"/>
F. Sacral anterior root stimulation (surgically implanted device that controls bladder flow)	<input type="checkbox"/>	<input type="checkbox"/>
G. Non-continent urinary diversion/ostomy (stoma, redirecting urine to an opening created in the abdomen)	<input type="checkbox"/>	<input type="checkbox"/>
H. Other method, specify _____	<input type="checkbox"/>	<input type="checkbox"/>

### 3. Do you use any collecting appliances for urinary incontinence?\*

☐ No                                      ☐ Yes, condom catheter/sheath (condom attached to a tube and collection bag)  
☐ Yes, diaper/pad                      ☐ Yes, ostomy bag  
☐ Yes, other, specify \_\_\_\_\_      ☐ Unknown

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

4. Has your method of bladder management changed during the time since your initial discharge from rehabilitation?

☐ No ☐ Yes Please explain: \_\_\_\_\_

5. What was the average number of hours per day that you spent on bladder management activities during the last 4 weeks? \_\_\_\_\_ Hours per day

### **C. Complications, Surgical Procedures and Symptoms**

#### **Urinary Tract Infections**

6. How many urinary tract infections have you had since your initial discharge from rehabilitation for which you have been treated? \_\_\_\_\_

#### **Kidney and Bladder Stones**

7. Were you diagnosed with a kidney stone on an x-ray, ultrasound or CT scan since your initial discharge from rehabilitation?

☐ No ☐ Yes Number of kidney stones \_\_\_\_\_ ☐ Yes: Number unknown

8. Were you treated for bladder stones since your initial discharge from rehabilitation? (If no, skip to Question 17)

☐ No  
☐ Yes: # of bladder stones \_\_\_\_\_ ☐ Yes: # unknown

#### **Incontinence**

9. Have you had any involuntary urine leakages (incontinence) since your initial discharge from rehabilitation?

☐ Daily ☐ Not every day but at least once per week  
☐ Not every week but at least once per month ☐ Less than once per month  
☐ Never

10. Have you had any change in urinary symptoms since your initial discharge from rehabilitation?

\_\_\_ No \_\_\_ Yes \_\_\_ Not applicable

If yes please explain: \_\_\_\_\_  
\_\_\_\_\_

### **F. Satisfaction and Lifestyle**

12. How big of an impact does bladder dysfunction have on your quality of life?\*

☐ Major Impact ☐ Some Impact ☐ Little Impact ☐ No Impact

13. How satisfied are you with your bladder management routine?

\_\_\_ Very Satisfied \_\_\_ Satisfied \_\_\_ Dissatisfied \_\_\_ Very Dissatisfied

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey



## Behavioral Adherence Assessment of Bowel and Bladder Treatment (BAABBT)

Instructions: *This measure should be administered in interview form by an interviewer with some basic knowledge of bowel and bladder care after SCI. It can be done by phone and/or face to face. Interviewer is encouraged to write down comments by the interviewee that may require further clarification. Complete the BAABB directly after the BBTI. For method specific questions, ask only about the pertinent methods, as determined during completion of the BBTI.*

Interviewer Statement:

- 1) We are examining the relationship between how you manage your bowel and bladder and your health. It is important that you answer honestly and as best you can remember. This information will not be seen by your health care providers.
- 2) I'm going to go through a list of recommendations that are often given for bowel and bladder management. Please tell me how often you (or someone providing you with assistance) have done these since your discharge from rehabilitation
  - *The responses are: Never (0%), Rarely (1 - 20% of the time); Sometime (21 - 69% of the time), Often (70 - 99 % of the time); Always (100% of the time); Not Applicable (NA)*

Bladder Management	Performed as recommended during the last month <i>never; rarely; sometimes; often; always</i>					
Universal bladder recommendations						
Wash hands prior to starting your bladder management program	Never	Rarely	Sometimes	Often	Always	NA
Void at least 4 times per day, with or without residual	Never	Rarely	Sometimes	Often	Always	NA
Adjust frequency and interval of voiding or catheterizations as needed	Never	Rarely	Sometimes	Often	Always	NA
Maintain supplies/equipment	Never	Rarely	Sometimes	Often	Always	NA
Adjust fluid intake as needed, drinking at least 6 cups of fluid a day.	Never	Rarely	Sometimes	Often	Always	NA
Wear appropriate gear / use appliances or supplies to keep skin dry <ul style="list-style-type: none"><li>During the day</li><li>At night</li></ul>	Never Never	Rarely Rarely	Sometimes Sometimes	Often Often	Always Always	NA NA
Take all recommended Bladder Medications <ul style="list-style-type: none"><li>Forget to take prescribed medications</li><li>Choose to not take prescribed medications</li><li>Add medications or supplements on your own</li></ul> List _____	Never Never Never	Rarely Rarely Rarely	Sometimes Sometimes Sometimes	Often Often Often	Always Always Always	NA NA NA
Communicate with health care provider when bladder problems occur	Never	Rarely	Sometimes	Often	Always	
Suggested / optional recommendations						
Limit intake of diuretics (caffeinated and diet drinks; alcohol)	Never	Rarely	Sometimes	Often	Always	NA
Change clothes as soon as they become wet	Never	Rarely	Sometimes	Often	Always	NA
Other recommended bladder management activities <ul style="list-style-type: none"><li>List _____</li><li>List _____</li><li>List _____</li></ul>	Never Never Never	Rarely Rarely Rarely	Sometimes Sometimes Sometimes	Often Often Often	Always Always Always	NA NA NA
Other activities that you regularly do for bladder management that were not recommended by your health care provider <ul style="list-style-type: none"><li>List _____</li><li>List _____</li></ul>	Never Never	Rarely Rarely	Sometimes Sometimes	Often Often	Always Always	NA NA

<b>Bowel Management</b>	How often did you perform this step during the last month <i>never; rarely; sometimes; often; always</i>					
<b>Universal Bowel Recommendations</b>						
Have supplies within reach	Never	Rarely	Sometimes	Often	Always	NA
Eat enough high fiber foods such as fruits and vegetables or take a fiber supplement	Never	Rarely	Sometimes	Often	Always	NA
Drink at least 6 cups of fluid a day	Never	Rarely	Sometimes	Often	Always	NA
Take more or less laxatives depending upon stool consistency	Never	Rarely	Sometimes	Often	Always	NA
Make other adjustments to medication or diet based on stool consistency	Never	Rarely	Sometimes	Often	Always	NA
Take all recommended oral Bowel Medication <ul style="list-style-type: none"> <li>• Forget to take prescribed medications</li> <li>• Choose to not take prescribed medications</li> <li>• Add medications or supplements on your own</li> </ul> List: _____	Never	Rarely	Sometimes	Often	Always	NA
Communicate with health care provider when having bowel related problems (such as constipation, bleeding, excessive pain, bloating)	Never	Rarely	Sometimes	Often	Always	NA

<b>Suggested / optional recommendations</b>						
Exercise 3 times per week for 30 minutes	Never	Rarely	Sometimes	Often	Always	NA
Engage in other physical activity for at least 30 minutes once per week.	Never	Rarely	Sometimes	Often	Always	NA
Sit on commode or toilet during bowel movements	Never	Rarely	Sometimes	Often	Always	NA
Perform bowel program 30 min to 1 hour after drinking a hot beverage or eating	Never	Rarely	Sometimes	Often	Always	NA
Other recommended bowel management activities <ul style="list-style-type: none"> <li>• List _____</li> <li>• List _____</li> <li>• List _____</li> </ul>	Never	Rarely	Sometimes	Often	Always	NA
Other activities that you do for bowel management that were not recommended by your health care provider <ul style="list-style-type: none"> <li>• List _____</li> <li>• List _____</li> <li>• List _____</li> </ul>	Never	Rarely	Sometimes	Often	Always	NA

<b>Other Health Management Activities – Regardless of whether they were recommended by a health care provider</b>	How often did you perform this step during the last month <i>never; rarely; sometimes; often; always</i>					
Used marijuana to make you feel better (If yes) For what are you using it? (If Yes) How do you intake marijuana?  (If yes) On average, how much do you use?	No    How often on average _____ Spasticity    Bowel Pain    Other _____ Eating (e.g. in baked goods)    Smoking    Vaporized Other _____ _____					
Drink cranberry juice or take cranberry supplement	Never	Rarely	Sometimes	Often	Always	NA

## Global Health Scale

Please respond to each item by marking one box per row.

		Excellent	Very good	Good	Fair	Poor
Global01	In general, would you say your health is: .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global02	In general, would you say your quality of life is:.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global03	In general, how would you rate your physical health? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global04	In general, how would you rate your mental health, including your mood and your ability to think?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global05	In general, how would you rate your satisfaction with your social activities and relationships? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global09	In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global06	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always						
Global10	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5						
		None	Mild	Moderate	Severe	Very severe						
Global08	How would you rate your fatigue on average? ....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5						
Global07	How would you rate your pain on average?.....	<input type="checkbox"/> 0 No pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10 Worst imaginable pain

## Emotional Distress – Anxiety – Short Form 8a

Please respond to each question or statement by marking one box per row.

In the past 7 days...

		Never	Rarely	Sometimes	Often	Always
EDANX01 1	I felt fearful.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX40 2	I found it hard to focus on anything other than my anxiety .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX41 3	My worries overwhelmed me.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX53 4	I felt uneasy .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX46 5	I felt nervous.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX07 6	I felt like I needed help for my anxiety .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX05 7	I felt anxious .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX54 8	I felt tense .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Emotional Distress – Depression – Short Form 8a

Please respond to each question or statement by marking one box per row.

**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always
EDDEP04 1	I felt worthless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP06 2	I felt helpless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP29 3	I felt depressed .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP41 4	I felt hopeless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP22 5	I felt like a failure .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP36 6	I felt unhappy .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP05 7	I felt that I had nothing to look forward to.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP09 8	I felt that nothing could cheer me up.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Fatigue – Short Form 8a

Please respond to each question or statement by marking one box per row.

**During the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
HI7 1	I feel fatigued .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

AN3 2	I have trouble <u>starting</u> things because I am tired.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**In the past 7 days...**

FATEXP41 3	How run-down did you feel on average? ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATEXP40 4	How fatigued were you on average? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATEXP35 5	How much were you bothered by your fatigue on average?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATIMP49 6	To what degree did your fatigue interfere with your physical functioning? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always
FATIMP3 7	How often did you have to push yourself to get things done because of your fatigue? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

FATIMP16 8	How often did you have trouble finishing things because of your fatigue? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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## Bladder Management Difficulties – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBL_31	I was frustrated by bladder accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_5	I worried that I would have a bladder accident.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_30	Bladder accidents limited my independence.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_23	I was sad/depressed because of problems with bladder functioning.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_Co m26	I worried about performing my bladder program in a public restroom.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_16	I worried about performing my bladder program.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBL_76	I had bladder accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_72	Bladder accidents have disrupted my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5



## Bladder Complications – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBL_21	A UTI (urinary tract infection) limited my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_28	I had an increase in spasms because of a UTI (urinary tract infection).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBL_50	I had a urinary tract infection.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_74	I had a urinary tract infection (UTI) that would not go away.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_Co m9	I avoided going out because of my urinary tract infection (UTI).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Bowel – Short Form**

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBO_33	I was frustrated by repeated bowel accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_Co m25	I worried that my social activities would be interrupted by a bowel accident.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_27	I worried I would have a bowel accident...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_4	Bowel accidents limited my independence.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_7	A bowel accident has affected my self-esteem.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_29	I was upset by problems with my bowel functioning.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_12	I worried about performing my bowel program.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBO_46	Bowel accidents have disrupted my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_52	I had bowel accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Positive Affect & Well-Being – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Never	Rarely	Sometimes	Often	Always
PPF_30	I thought positively about my future.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF17	My life had meaning.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF20	My life had purpose.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
PPF_32	I was thankful to be alive.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF12	I felt hopeful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF19	My life was worth living.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF15	My life was satisfying.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF14	I had a sense of well-being.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF16	I had a sense of balance in my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF22	I felt cheerful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF06	I looked forward with enjoyment to upcoming events.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF21	I was living life to the fullest.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF07	Many areas of my life were interesting to me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Ability to Participate in Social Roles – Short Form

**Please respond to each question or statement by marking one box per row.**

	<b>In the past 7 days...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
NQPRF01	I can keep up with my family responsibilities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF08	I am able to socialize with my friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF11	I can do everything for my friends that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF32	I am able to perform my daily routines.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF34	I can keep up with my work responsibilities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF06	I am able to do all of the family activities that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF14	I am able to do all of the activities with friends that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF17	I can keep up with my social commitments.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF18	I am able to do all of my regular leisure activities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF27	I can do all the leisure activities that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Satisfaction With Social– Short Form

Please respond to each question or statement by marking one box per row.

	In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
SRPSAT10	I am satisfied with my current level of social activity.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT23	I am satisfied with my ability to do leisure activities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT25	I am satisfied with my current level of activities with my friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT48	I am satisfied with my ability to do things for fun at home (like reading; listening to music; etc.).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT49	I am satisfied with my ability to perform my daily routines.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very Much
NQSAT02	I am disappointed in my ability to meet the needs of my family.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT03	I am bothered by my limitations in regular family activities.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT13	I am disappointed in my ability to socialize with friends.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT39	I am disappointed in my ability to take care of personal and household responsibilities.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT40	I am bothered by limitations in performing my work (include work at home).	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

## Spinal Cord Injury Lifestyle Scale

Pruitt 1998

During the last three months how often have you done the following activities?

	Never	Rarely	Sometimes	Frequently	Almost Always
<b>Cardiovascular</b>					
1. I avoid smoking cigarettes.	0	1	2	3	4
2. I limit the amount of fat and cholesterol in my diet (for example, I limit red meats, dairy products).	0	1	2	3	4
3. I am aware of and try to reduce my risk for heart disease.	0	1	2	3	4
4. I monitor my blood pressure on a regular basis.	0	1	2	3	4
<b>Genitourinary</b>					
1. I use an intermittent catheterization program and stick to the recommended schedule.	0	1	2	3	4
2. I change my catheters as often as I have been directed to.	0	1	2	3	4
3. I have episodes of bladder incontinence.	0	1	2	3	4
4. I use a rectal suppository as part of my regular bowel program.	0	1	2	3	4
<b>Neuromusculoskeletal</b>					
1. I do range of motion exercises daily to keep my joints flexible.	0	1	2	3	4
2. I do exercises that enhance my muscle strength (for example, weight training) at least 3 times a week.	0	1	2	3	4
3. My muscle strengthening exercises are monitored by a therapist at least once a year.	0	1	2	3	4
4. I allow my shoulder joints to rest when I am having pain from overusing them.	0	1	2	3	4
5. I do activities which put weight on the bones in my legs to help increase bone density about 3 times a week (for example, use standing frame).	0	1	2	3	4
6. I pay attention to the position my body is in when I am in my wheelchair.	0	1	2	3	4
7. I pay attention to the position my body is in when I am sleeping.	0	1	2	3	4
8. If I noticed the beginning of a contracture (a joint that is 'freezing up'), I would know exactly what to do.	0	1	2	3	4

	Never	Rarely	Sometimes	Frequently	Almost Always
<b>Skin</b>					
1. I check my skin to look for any areas of redness or breakdown.	0	1	2	3	4
2. I do some type of pressure relief every 30 minutes any time I am in my chair or driving.	0	1	2	3	4
3. I am careful not to bump my legs, feet, or buttocks when doing transfers.	0	1	2	3	4
4. I wear something on my feet when I am out of bed (for example, shoes or foam boots).	0	1	2	3	4
5. I am careful when handling hot liquids by not carrying them in my lap.	0	1	2	3	4
6. I am aware of the condition of my wheelchair cushion.	0	1	2	3	4
7. I am aware of the condition and repair needs of my wheelchair.	0	1	2	3	4
<b>Psychosocial</b>					
1. I am able to get around in my house (my house is wheelchair accessible).	0	1	2	3	4
2. I am with or talk to other people at least once a day.	0	1	2	3	4

## Quality of Caregiving Measure

Please answer the following questions:

1. Current number of paid assistants per month \_\_\_\_\_.
2. Average number of hours of paid assistance per day \_\_\_\_\_.
3. Current number of non-paid assistants per month \_\_\_\_\_.
4. Average number of hours of non-paid (i.e. family caregiver) assistance per day \_\_\_\_\_.
5. The total number of different assistants/caregivers in the past year (12 month period) has been: \_\_\_\_\_. Do you consider this to be:  
Too many      Just right      Too few
6. The total number of hours of caregiver assistance that you receive per day is: \_\_\_\_\_. Do you consider this to be:  
Too much      Satisfactory      Too little

---

**The following questions ask about your relationship with your primary personal care attendant/caregiver. For the purposes of this questionnaire, a primary personal attendant/caregiver will be defined as the caregiver with whom you spend the most (waking) hours per week. Is this person a paid attendant? (please circle yes or no)**

1. How is communication between yourself and (name of primary personal care attendant/caregiver)-how well can you exchange ideas or talk about things that really concern you?  
Not at all well      Fairly well      Well      Very well
2. In general, how similar are your views about life to those of (name of care recipient)?  
Not at all similar      Fairly similar      Similar      Very similar
3. Generally, how well do you and (name of primary personal care attendant/caregiver) get along together?  
Not at all well      Fairly well      Well      Very well
4. Taking everything into consideration, how close do you feel in the relationship between you and (name of primary personal care attendant/caregiver)?  
Not at all close      Fairly close      Close      Very close



---

**How important are the following to the success of your relationship with ANY personal care attendant/caregiver:**

**5. Your attendant's skill level**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**6. Your attendant's willingness to receive training and input regarding your care**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**7. Professionalism (on the part of the attendant/caregiver)**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**8. Your professionalism/skills as an employer**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**9. Communication**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**10. Your attendant's reliability**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**11. Mutual respect**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**12. Mutual trust**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**13. Warmth**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**14. Your attendant's respect for your privacy**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**15. Your attendant's treatment of you as a competent person**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**Please select and rank in order of importance the three most important issues from the previous list (items 1-15) with regard to your relationship with any personal care attendant/caregiver:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

---

**Please answer the following:**

1. Do you feel you need more training to act effectively as an employer of a paid personal care attendant? Circle **yes** or **no**.

Finally, please feel free to add any additional comments or concerns about personal care attendants/caregivers issues in the space below. Thank you very much.

<b>Completion Date</b>	/ /
<b>Participant ID</b>	
<b>Interviewer</b>	

## **MEASURES PACKET**

Please be honest and thorough as possible. Someone from our staff will contact you soon to schedule an interview to complete these questions. The interview can be in person or by phone. It must be completed within two weeks of completing the face-to-face interview. Please review these items prior to that meeting.

**Thank you for being part of our study!**

## Personal Characteristics Form – Subjects with SCI

Gender: ☐ Male ☐ Female

Race: ☐ Caucasian ☐ African American ☐ Asian ☐ Other \_\_\_\_\_

Ethnicity: ☐ Not Hispanic ☐ Hispanic

Date of Injury: \_\_\_\_\_

Age at Injury: \_\_\_\_\_

Current Age: \_\_\_\_\_

Etiology of SCI: ☐ Vehicular ☐ Sports ☐ Fall ☐ Violence ☐ Other \_\_\_\_\_

Have You Served in the U.S. Military? ☐ Yes ☐ No

Marital Status Currently

☐ Single, Never Married ☐ Married ☐ Significant Other ☐ Divorced  
☐ Separated ☐ Widowed

Marital Status at Injury

☐ Single, Never Married ☐ Married ☐ Significant Other ☐ Divorced  
☐ Separated ☐ Widowed

Current Vocational Status (Check all that apply, place an X in primary category):

☐ Employed ☐ Homemaker ☐ Student ☐ Unemployed ☐ Retired - Age  
☐ Retired – Disability ☐ Other \_\_\_\_\_

Vocational Status at Injury (Check all that apply, place an X in primary category):

☐ Employed ☐ Homemaker ☐ Student ☐ Unemployed ☐ Retired  
☐ Other \_\_\_\_\_

Highest Level of Education Completed

☐ 8<sup>th</sup> grade or less ☐ 9<sup>th</sup>-11<sup>th</sup> grade ☐ High School or GED ☐ Associates Degree  
☐ Bachelor's Degree ☐ Master's Degree ☐ Doctorate ☐ Other \_\_\_\_\_

Living Situation (Select all that apply)

☐ Live Alone ☐ Live with Spouse/SO ☐ Live with Parents ☐ Live with Children  
☐ Live with Paid Caregiver ☐ Live with Roommates ☐ Live with Other \_\_\_\_\_

If Living with Children (Number)

☐ 0 – 4 years old ☐ 5-18 years old ☐ Adult

Nature of Spinal Cord Injury

☐ Incomplete Paraplegia    ☐ Complete Paraplegia  
☐ Incomplete Tetraplegia    ☐ Complete Tetraplegia

Household Income (from all sources)

☐ < \$25,000    ☐ \$25,000 - \$49,999    ☐ \$50,000 - \$74,999    ☐ > \$80,000

Primary Payer for Health Care

☐ Auto No-Fault    ☐ Other Private    ☐ Workers' Compensation    ☐ Medicare  
☐ Medicaid    ☐ Veterans Administration    ☐ Self Pay    ☐ Other \_\_\_\_\_

What is Your Primary Source of Transportation?

☐ Car - Yours    ☐ Car – Someone Else's    ☐ Public Transportation  
☐ Other \_\_\_\_\_

Do You Have a Caregiver Who Assists you with Bowel and/or Bladder Management?

☐ Yes    ☐ No

**Spinal Cord Injury Bowel and Bladder Treatment Index Short Form (SCI-BBTI-SF)\***

Date of Data Collection: MMDDYYYY \_\_\_\_\_

Site of data collection: Clinic \_\_\_\_ Phone \_\_\_\_ Other \_\_\_\_\_

SCIMS Subject Identification Code: \_\_\_\_\_ Data Collector Initials: \_\_\_\_\_

Instructions to the subject: This questionnaire asks about your methods of bowel and bladder management, complications and related health and well-being issues. It includes questions about the medications that you take, symptoms and complications you may have experienced and other related issues. Let me know if you have any questions. Please note that the time of reference is not the same for all of the questions. Also, for some questions, more than one answer may be applicable.

**BOWEL**

**A. Bowel Management Methods**

**1. What have been your methods of defecation and bowel care during the last 4 weeks? If you use more than one method, classify the method that you use most often as your main method and the others as supplementary methods. If you always use two methods, classify both as main methods.**

	Main*	Supplementary*
Normal Defecation (require no special procedures or devices)	<input type="checkbox"/>	<input type="checkbox"/>
Straining/ bearing down to empty	<input type="checkbox"/>	<input type="checkbox"/>
Digital ano-rectal stimulation ( <u>circular stimulation of the anal canal &amp; rectum w/ finger to assist with bowel evacuation</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Rectal Suppositories	<input type="checkbox"/>	<input type="checkbox"/>
Digital evacuation ( <u>using finger to help remove stools</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Enema (> 150 mL)	<input type="checkbox"/>	<input type="checkbox"/>
Other Flushing, e.g., Peristeen™ ( <u>using warm water from a tube placed in the rectum to stimulate the colon to release stool</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Colostomy ( <u>always a main method</u> )	<input type="checkbox"/>	<input type="checkbox"/>
Electrical Implant to Stimulate Bowel Function	<input type="checkbox"/>	<input type="checkbox"/>
Oral laxatives / Medications	<input type="checkbox"/>	<input type="checkbox"/>
Other method _____	<input type="checkbox"/>	<input type="checkbox"/>

**1a. If you do digital stimulation or evacuation, how frequently do you do this?\***

- ☐ Less than once every week      ☐ Once per week or more but not daily  
☐ Daily      ☐ Other: \_\_\_\_\_

**2. Has your method of bowel management changed during the last year?**

- ☐ No      ☐ Yes Please explain: \_\_\_\_\_

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

3. During the last year, how independent have you been with your bowel management routine?\*
- ☐ Require total assistance      ☐ Require partial assistance; does not clean self
- ☐ Require some assistance; clean self independently
- ☐ Use toilet independently but need adaptive devices or special setting (e.g. bars)
- ☐ Use toilet independently
4. What was the average number of hours per day that you spent on bowel management activities during the last 4 weeks. \_\_\_\_ Hours per day
5. On average how much time did you spend on each defecation during the last year?
- ☐ Less than 30 minutes      ☐ 31-60 minutes      ☐ More than an hour
6. How often have you had a bowel movement on average during the last 4 weeks?
- ☐ Daily      ☐ 2-6 times per week      ☐ Less than once per week
7. During the last year, have you experienced uneasiness, sweating or headaches during or after bowel movements?
- ☐ No      ☐ Yes
8. Do you take medication (tablets, liquids or drops) to treat constipation?
- ☐ No      ☐ Yes:      ☐ tablets      ☐ drops or liquids
9. Do you take medication for fecal incontinence?
- ☐ No      ☐ Yes
10. During the last year, how often have you had episodes of gas?\*
- ☐ At least daily      ☐ Not every day but at least once per week
- ☐ Not every week but at least once per month      ☐ Less than once per month
- ☐ Never      ☐ Not Applicable – no sensation

### **B. Complications, Symptoms and Surgical Procedures**

11. Have you ever been bothered by any of these problems during the last year?\*
- ☐ Hemorrhoids      ☐ Sores around the anus      ☐ Fissures (a crack inside the anus)
- ☐ Rectal Abscess (pus collects in the anal/rectal area)
- ☐ Rectal prolapse (the inside of the rectum turns inside out and comes out of the anus)
- ☐ Anal skin problems      ☐ Other \_\_\_\_\_
12. Do you have chronic constipation?      ☐ No      ☐ Yes

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

**13. During the last year, how often have you had incontinence resulting in either liquid or solid stools?\***

- |   |   |
|---|---|
| <input type="checkbox"/> Two or more times daily                    | <input type="checkbox"/> Daily                    |
| <input type="checkbox"/> Not every day but at least once per week   |   |
| <input type="checkbox"/> Not every week but at least once per month | <input type="checkbox"/> Less than once per month |
| <input type="checkbox"/> Never                                      | <input type="checkbox"/> Not Applicable           |

### **C. Satisfaction and Lifestyle**

**14. How big of an impact does bowel dysfunction have on your quality of life?\***

- ☐ Major Impact      ☐ Some Impact      ☐ Little Impact      ☐ No Impact

**15. How satisfied are you with your bowel management routine?\*\***

- ☐ Very Satisfied      ☐ Satisfied      ☐ Dissatisfied      ☐ Very Dissatisfied

**16. How flexible is your bowel management routine?\*\*** (Only read response choices if subjects ask for clarification of terms)

- ☐ Very flexible (I often change the time or frequency at which I manage my bowels.)
- ☐ Quite flexible (I can delay management or alter the timing if I want to.)
- ☐ Not very flexible (I don't usually change my routine unless it is unavoidable.)
- ☐ Not flexible at all (I will not go to activities if they clash with my bowel management time.)

\* Adapted from the International SCI Standards and Data Sets

º Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey



## BLADDER

**Instructions:** The following questions concern how you manage your bladder since your SCI. Please let me know if you have any questions as you answer them.

### 1. Are you aware of the need to empty your bladder?\*

☐ No      ☐ Yes      ☐ Not applicable

### A. Bladder Management Methods

### 2. What have been your methods of bladder voiding and bladder care during the last 4 weeks? If you use more than one method, classify the method that you use the most as your main method and others as supplementary ones. If you always use two methods, classify them both as main methods and any others as supplementary ones.\*

	Main	Supplementary
A. Normal Voiding (voluntary initiation of urination w/o reflex stimulation or compression of the bladder)	<input type="checkbox"/>	<input type="checkbox"/>
B. Bladder reflex triggering		
Voluntary (tapping on bladder area, stretching to facilitate drainage)	<input type="checkbox"/>	<input type="checkbox"/>
Involuntary (incontinent using a diaper or condom cath; not aware of voiding)	<input type="checkbox"/>	<input type="checkbox"/>
C. Bladder expression		
Straining (abdominal straining, Valsalva's manoeuvre)	<input type="checkbox"/>	<input type="checkbox"/>
External compression (Credé manoeuvre manual pressure on the lower abdominal wall)	<input type="checkbox"/>	<input type="checkbox"/>
D. Intermittent catheterization (periodically inserting a cath from the urethra to the bladder to allow urine to drain)		
Self-catheterization	<input type="checkbox"/>	<input type="checkbox"/>
Catheterization by attendant	<input type="checkbox"/>	<input type="checkbox"/>
E. Indwelling catheter (catheter is housed inside the body)		
Transurethral (IC is attached to a collection bag and stays in the bladder all of the time changed weekly or less, eg, Foley. Some patients leave IC in at night and self-cath during the day)	<input type="checkbox"/>	<input type="checkbox"/>
Suprapubic (surgically placed, inserted through the abdomen)	<input type="checkbox"/>	<input type="checkbox"/>
F. Sacral anterior root stimulation (surgically implanted device that controls bladder flow)	<input type="checkbox"/>	<input type="checkbox"/>
G. Non-continent urinary diversion/ostomy (stoma, redirecting urine to an opening created in the abdomen)	<input type="checkbox"/>	<input type="checkbox"/>
H. Other method, specify _____	<input type="checkbox"/>	<input type="checkbox"/>

### 3. Do you use any collecting appliances for urinary incontinence?\*

☐ No      ☐ Yes, condom catheter/sheath (condom attached to a tube and collection bag)  
☐ Yes, diaper/pad      ☐ Yes, ostomy bag  
☐ Yes, other, specify \_\_\_\_\_      ☐ Unknown

### 4. Has your method of bladder management changed during the last year?

☐ No      ☐ Yes Please explain: \_\_\_\_\_

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

5. What was the average number of hours per day that you spent on bowel management activities during the last 4 weeks? \_\_\_\_\_ Hours per day

### **C. Complications, Symptoms and Surgical Procedures**

#### **Urinary Tract Infections**

6. How many urinary tract infections have you had during the past year for which you have been treated? \_\_\_\_\_

#### **Kidney and Bladder Stones**

7. Were you diagnosed with a kidney stone on an x-ray, ultrasound or CT scan during the past year?

☐ No    ☐ Yes Number of kidney stones \_\_\_\_\_ ☐ Yes: Number unknown

8. Were you treated for bladder stones during the past year?

☐ No    ☐ Yes: # of bladder stones \_\_\_\_\_ ☐ Yes: # unknown

#### **Incontinence**

9. Have you had any involuntary urine leakages (incontinence) during the last year?\*

☐ Daily    ☐ Not every day but at least once per week  
☐ Not every week but at least once per month    ☐ Less than once per month  
☐ Never

10. Have you had any change in urinary symptoms during the last year?\*

\_\_\_ No    \_\_\_ Yes    \_\_\_ Not applicable

If yes please explain: \_\_\_\_\_

### **C. Satisfaction and Lifestyle**

12. How big of an impact does bladder dysfunction have on your quality of life?\*

☐ Major Impact    ☐ Some Impact    ☐ Little Impact    ☐ No Impact

13. How satisfied are you with your bladder management routine?

\_\_\_ Very Satisfied    \_\_\_ Satisfied    \_\_\_ Dissatisfied    \_\_\_ Very Dissatisfied

\* Adapted from the International SCI Standards and Data Sets

° Adapted from NBD

\*\* Adapted from the Coggrave Bowel Care Survey

## Behavioral Adherence Assessment of Bowel and Bladder Treatment (BAABBT)

**Instructions:** *This measure should be administered in interview form by an interviewer with some basic knowledge of bowel and bladder care after SCI. It can be done by phone and/or face to face. Interviewer is encouraged to write down comments by the interviewee that may require further clarification. Complete the BAABB directly after the BBTI. For method specific questions, ask only about the pertinent methods, as determined during completion of the BBTI.*

Interviewer Statement:

- 1) We are examining the relationship between what you do to manage your bowel and bladder and your health. It is important that you answer honestly and as best you can remember. This information will not be seen by your health care providers.
- 2) I'm going to go through a list of recommendations that are often given for bowel and bladder management. Please tell me how often you (or someone providing you with assistance) have done these during the last year
  - **The responses are:**  
*Never (0%), Rarely (1 - 20% of the time); Sometime (21 - 69% of the time), Often (70 - 99 % of the time); Always (100% of the time); Not Applicable (NA)*

Bladder Management	Performed as recommended during the last month <i>never; rarely; sometimes; often; always</i>					
Universal bladder recommendations						
Wash hands prior to starting your bladder management program	Never	Rarely	Sometimes	Often	Always	NA
Void at least 4 times per day, with or without residual	Never	Rarely	Sometimes	Often	Always	NA
Adjust frequency and interval of voiding or catheterizations as needed	Never	Rarely	Sometimes	Often	Always	NA
Maintain supplies/equipment	Never	Rarely	Sometimes	Often	Always	NA
Adjust fluid intake as needed, drinking at least 6 cups of fluid a day.	Never	Rarely	Sometimes	Often	Always	NA
Wear appropriate gear / use appliances or supplies to keep skin dry						
• During the day	Never	Rarely	Sometimes	Often	Always	NA
• At night	Never	Rarely	Sometimes	Often	Always	NA
Take all recommended Bladder Medications						
• Forget to take prescribed medications	Never	Rarely	Sometimes	Often	Always	NA
• Choose to not take prescribed medications	Never	Rarely	Sometimes	Often	Always	NA
• Add medications or supplements on your own	Never	Rarely	Sometimes	Often	Always	NA
List _____						
Communicate with health care provider when bladder problems occur	Never	Rarely	Sometimes	Often	Always	
Suggested / optional recommendations						
Limit intake of diuretics (caffeinated and diet drinks; alcohol)	Never	Rarely	Sometimes	Often	Always	NA
Change clothes as soon as they become wet	Never	Rarely	Sometimes	Often	Always	NA
Other recommended bladder management activities						
• List _____	Never	Rarely	Sometimes	Often	Always	NA
• List _____	Never	Rarely	Sometimes	Often	Always	NA
• List _____	Never	Rarely	Sometimes	Often	Always	NA
Other activities that you regularly do for bladder management that were not recommended by your health care provider						
• List _____	Never	Rarely	Sometimes	Often	Always	NA
• List _____	Never	Rarely	Sometimes	Often	Always	NA

<b>Bowel Management</b>	How often did you perform this step during the last month <i>never; rarely; sometimes; often; always</i>					
<b>Universal Bowel Recommendations</b>						
Have supplies within reach	Never	Rarely	Sometimes	Often	Always	NA
Eat enough high fiber foods such as fruits and vegetables or take a fiber supplement	Never	Rarely	Sometimes	Often	Always	NA
Drink at least 6 cups of fluid a day	Never	Rarely	Sometimes	Often	Always	NA
Take more or less laxatives depending upon stool consistency	Never	Rarely	Sometimes	Often	Always	NA
Make other adjustments to medication or diet based on stool consistency	Never	Rarely	Sometimes	Often	Always	NA
Take all recommended oral Bowel Medication <ul style="list-style-type: none"> <li>• Forget to take prescribed medications</li> <li>• Choose to not take prescribed medications</li> <li>• Add medications or supplements on your own</li> </ul> List: _____	Never	Rarely	Sometimes	Often	Always	NA
Communicate with health care provider when having bowel related problems (such as constipation, bleeding, excessive pain, bloating)	Never	Rarely	Sometimes	Often	Always	NA

<b>Suggested / optional recommendations</b>						
Exercise 3 times per week for 30 minutes	Never	Rarely	Sometimes	Often	Always	NA
Engage in other physical activity for at least 30 minutes once per week.	Never	Rarely	Sometimes	Often	Always	NA
Sit on commode or toilet during bowel movements	Never	Rarely	Sometimes	Often	Always	NA
Perform bowel program 30 min to 1 hour after drinking a hot beverage or eating	Never	Rarely	Sometimes	Often	Always	NA
Other recommended bowel management activities <ul style="list-style-type: none"> <li>• List _____</li> <li>• List _____</li> <li>• List _____</li> </ul>	Never	Rarely	Sometimes	Often	Always	NA
Other activities that you do for bowel management that were not recommended by your health care provider <ul style="list-style-type: none"> <li>• List _____</li> <li>• List _____</li> <li>• List _____</li> </ul>	Never	Rarely	Sometimes	Often	Always	NA

<b>Other Health Management Activities – Regardless of whether they were recommended by a health care provider</b>	How often did you perform this step during the last month <i>never; rarely; sometimes; often; always</i>					
Used marijuana to make you feel better (If yes) For what are you using it? (If Yes) How do you intake marijuana?  (If yes) On average, how much do you use?	No    How often on average _____ Spasticity    Bowel Pain    Other _____ Eating (e.g. in baked goods)    Smoking    Vaporized Other _____ _____					
Drink cranberry juice or take cranberry supplement	Never	Rarely	Sometimes	Often	Always	NA

## Global Health Scale

Please respond to each item by marking one box per row.

		Excellent	Very good	Good	Fair	Poor
Global01	In general, would you say your health is: .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global02	In general, would you say your quality of life is:.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global03	In general, how would you rate your physical health? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global04	In general, how would you rate your mental health, including your mood and your ability to think?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global05	In general, how would you rate your satisfaction with your social activities and relationships? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global09	In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
Global06	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? .....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always						
Global10	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5						
		None	Mild	Moderate	Severe	Very severe						
Global08	How would you rate your fatigue on average? ....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5						
Global07	How would you rate your pain on average?.....	<input type="checkbox"/> 0 No pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10 Worst imaginable pain

## Emotional Distress – Anxiety – Short Form 8a

Please respond to each question or statement by marking one box per row.

In the past 7 days...

		Never	Rarely	Sometimes	Often	Always
EDANX01 1	I felt fearful.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX40 2	I found it hard to focus on anything other than my anxiety .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX41 3	My worries overwhelmed me.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX53 4	I felt uneasy .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX46 5	I felt nervous.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX07 6	I felt like I needed help for my anxiety .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX05 7	I felt anxious .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX54 8	I felt tense .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Emotional Distress – Depression – Short Form 8a

Please respond to each question or statement by marking one box per row.

**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always
EDDEP04 1	I felt worthless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP06 2	I felt helpless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP29 3	I felt depressed .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP41 4	I felt hopeless .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP22 5	I felt like a failure .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP36 6	I felt unhappy .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP05 7	I felt that I had nothing to look forward to.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDDEP09 8	I felt that nothing could cheer me up.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5



## Fatigue – Short Form 8a

Please respond to each question or statement by marking one box per row.

**During the past 7 days...**

		Not at all	A little bit	Somewhat	Quite a bit	Very much
HI7 1	I feel fatigued .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

AN3 2	I have trouble <u>starting</u> things because I am tired.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**In the past 7 days...**

FATEXP41 3	How run-down did you feel on average? ...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATEXP40 4	How fatigued were you on average? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATEXP35 5	How much were you bothered by your fatigue on average?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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FATIMP49 6	To what degree did your fatigue interfere with your physical functioning? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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**In the past 7 days...**

		Never	Rarely	Sometimes	Often	Always
FATIMP3 7	How often did you have to push yourself to get things done because of your fatigue? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

FATIMP16 8	How often did you have trouble finishing things because of your fatigue? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
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## Bladder Management Difficulties – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBL_31	I was frustrated by bladder accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_5	I worried that I would have a bladder accident.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_30	Bladder accidents limited my independence.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_23	I was sad/depressed because of problems with bladder functioning.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_Co m26	I worried about performing my bladder program in a public restroom.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_16	I worried about performing my bladder program.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBL_76	I had bladder accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_72	Bladder accidents have disrupted my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Bladder Complications – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBL_21	A UTI (urinary tract infection) limited my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_28	I had an increase in spasms because of a UTI (urinary tract infection).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBL_50	I had a urinary tract infection.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_74	I had a urinary tract infection (UTI) that would not go away.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBL_Co m9	I avoided going out because of my urinary tract infection (UTI).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**Bowel – Short Form**

Please respond to each question or statement by marking one box per row.

	Lately...	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
rToiletBO_33	I was frustrated by repeated bowel accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_Co m25	I worried that my social activities would be interrupted by a bowel accident.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_27	I worried I would have a bowel accident...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_4	Bowel accidents limited my independence.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_7	A bowel accident has affected my self-esteem.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_29	I was upset by problems with my bowel functioning.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_12	I worried about performing my bowel program.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	Lately...	Never	Rarely	Sometimes	Often	Always
rToiletBO_46	Bowel accidents have disrupted my daily activities.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
rToiletBO_52	I had bowel accidents.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Positive Affect & Well-Being – Short Form

Please respond to each question or statement by marking one box per row.

	Lately...	Never	Rarely	Sometimes	Often	Always
PPF_30	I thought positively about my future.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF17	My life had meaning.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF20	My life had purpose.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
PPF_32	I was thankful to be alive.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF12	I felt hopeful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF19	My life was worth living.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF15	My life was satisfying.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF14	I had a sense of well-being.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF16	I had a sense of balance in my life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF22	I felt cheerful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF06	I looked forward with enjoyment to upcoming events.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF21	I was living life to the fullest.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPPF07	Many areas of my life were interesting to me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Ability to Participate in Social Roles – Short Form

**Please respond to each question or statement by marking one box per row.**

	<b>In the past 7 days...</b>	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
NQPRF01	I can keep up with my family responsibilities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF08	I am able to socialize with my friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF11	I can do everything for my friends that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF32	I am able to perform my daily routines.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF34	I can keep up with my work responsibilities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF06	I am able to do all of the family activities that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF14	I am able to do all of the activities with friends that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF17	I can keep up with my social commitments.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF18	I am able to do all of my regular leisure activities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
NQPRF27	I can do all the leisure activities that I want to do.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

## Satisfaction With Social– Short Form

Please respond to each question or statement by marking one box per row.

	In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very much
SRPSAT10	I am satisfied with my current level of social activity.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT23	I am satisfied with my ability to do leisure activities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT25	I am satisfied with my current level of activities with my friends.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT48	I am satisfied with my ability to do things for fun at home (like reading; listening to music; etc.).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
SRPSAT49	I am satisfied with my ability to perform my daily routines.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

	In the past 7 days...	Not at all	A little bit	Somewhat	Quite a bit	Very Much
NQSAT02	I am disappointed in my ability to meet the needs of my family.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT03	I am bothered by my limitations in regular family activities.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT13	I am disappointed in my ability to socialize with friends.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT39	I am disappointed in my ability to take care of personal and household responsibilities.	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
NQSAT40	I am bothered by limitations in performing my work (include work at home).	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1

## Spinal Cord Injury Lifestyle Scale

Pruitt 1998

During the last three months how often have you done the following activities?

	Never	Rarely	Sometimes	Frequently	Almost Always
<b>Cardiovascular</b>					
1. I avoid smoking cigarettes.	0	1	2	3	4
2. I limit the amount of fat and cholesterol in my diet (for example, I limit red meats, dairy products).	0	1	2	3	4
3. I am aware of and try to reduce my risk for heart disease.	0	1	2	3	4
4. I monitor my blood pressure on a regular basis.	0	1	2	3	4
<b>Genitourinary</b>					
1. I use an intermittent catheterization program and stick to the recommended schedule.	0	1	2	3	4
2. I change my catheters as often as I have been directed to.	0	1	2	3	4
3. I have episodes of bladder incontinence.	0	1	2	3	4
4. I use a rectal suppository as part of my regular bowel program.	0	1	2	3	4
<b>Neuromusculoskeletal</b>					
1. I do range of motion exercises daily to keep my joints flexible.	0	1	2	3	4
2. I do exercises that enhance my muscle strength (for example, weight training) at least 3 times a week.	0	1	2	3	4
3. My muscle strengthening exercises are monitored by a therapist at least once a year.	0	1	2	3	4
4. I allow my shoulder joints to rest when I am having pain from overusing them.	0	1	2	3	4
5. I do activities which put weight on the bones in my legs to help increase bone density about 3 times a week (for example, use standing frame).	0	1	2	3	4
6. I pay attention to the position my body is in when I am in my wheelchair.	0	1	2	3	4
7. I pay attention to the position my body is in when I am sleeping.	0	1	2	3	4
8. If I noticed the beginning of a contracture (a joint that is 'freezing up'), I would know exactly what to do.	0	1	2	3	4



	Never	Rarely	Sometimes	Frequently	Almost Always
<b>Skin</b>					
1. I check my skin to look for any areas of redness or breakdown.	0	1	2	3	4
2. I do some type of pressure relief every 30 minutes any time I am in my chair or driving.	0	1	2	3	4
3. I am careful not to bump my legs, feet, or buttocks when doing transfers.	0	1	2	3	4
4. I wear something on my feet when I am out of bed (for example, shoes or foam boots).	0	1	2	3	4
5. I am careful when handling hot liquids by not carrying them in my lap.	0	1	2	3	4
6. I am aware of the condition of my wheelchair cushion.	0	1	2	3	4
7. I am aware of the condition and repair needs of my wheelchair.	0	1	2	3	4
<b>Psychosocial</b>					
1. I am able to get around in my house (my house is wheelchair accessible).	0	1	2	3	4
2. I am with or talk to other people at least once a day.	0	1	2	3	4

## Quality of Caregiving Measure

Please answer the following questions:

1. Current number of paid assistants per month \_\_\_\_\_.
2. Average number of hours of paid assistance per day \_\_\_\_\_.
3. Current number of non-paid assistants per month \_\_\_\_\_.
4. Average number of hours of non-paid (i.e. family caregiver) assistance per day \_\_\_\_\_.
5. The total number of different assistants/caregivers in the past year (12 month period) has been: \_\_\_\_\_. Do you consider this to be:  
Too many      Just right      Too few
6. The total number of hours of caregiver assistance that you receive per day is: \_\_\_\_\_. Do you consider this to be:  
Too much      Satisfactory      Too little

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**The following questions ask about your relationship with your primary personal care attendant/caregiver. For the purposes of this questionnaire, a primary personal attendant/caregiver will be defined as the caregiver with whom you spend the most (waking) hours per week. Is this person a paid attendant? (please circle yes or no)**

1. How is communication between yourself and (name of primary personal care attendant/caregiver)-how well can you exchange ideas or talk about things that really concern you?  
Not at all well      Fairly well      Well      Very well
2. In general, how similar are your views about life to those of (name of care recipient)?  
Not at all similar      Fairly similar      Similar      Very similar
3. Generally, how well do you and (name of primary personal care attendant/caregiver) get along together?  
Not at all well      Fairly well      Well      Very well
4. Taking everything into consideration, how close do you feel in the relationship between you and (name of primary personal care attendant/caregiver)?  
Not at all close      Fairly close      Close      Very close

---

**How important are the following to the success of your relationship with ANY personal care attendant/caregiver:**

**5. Your attendant's skill level**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**6. Your attendant's willingness to receive training and input regarding your care**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**7. Professionalism (on the part of the attendant/caregiver)**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**8. Your professionalism/skills as an employer**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**9. Communication**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**10. Your attendant's reliability**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**11. Mutual respect**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**12. Mutual trust**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**13. Warmth**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**14. Your attendant's respect for your privacy**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**15. Your attendant's treatment of you as a competent person**

*Very important      Somewhat important      Somewhat unimportant      Very unimportant*

**Please select and rank in order of importance the three most important issues from the previous list (items 1-15) with regard to your relationship with any personal care attendant/caregiver:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

---

**Please answer the following:**

1. Do you feel you need more training to act effectively as an employer of a paid personal care attendant? Circle **yes** or **no**.

Finally, please feel free to add any additional comments or concerns about personal care attendants/caregivers issues in the space below. Thank you very much.

## **BBTI 1a**

Once every week

More than once a week

Daily

Other

Unknown

## **BBTI 5**

Less than 30 minutes

31-60 minutes

More than an hour

## **BBTI 10**

- At least daily
- Not every day but at least once per week
- Not every week but at least once per month
- Less than once per month
- Never
- N/A – no sensation

## **BBTI 3**

- **Total assistance**
- **Partial assistance:** do not clean self
- **Some assistance:** clean self
- **Use toilet independently:** need adaptive equipment or special setting
- **Use toilet independently**

## **BBTI 6**

Daily

2-6 times per week

Less than once per week

## **BBTI 14**

Major impact

Some impact

Little impact

No impact

## **BBTI 16**

- **Very flexible** (I often change time/frequency of program)
- **Quite flexible** (I can delay management or alter timing if I want to)
- **Not very flexible** (I don't usually change my routine unless it is unavoidable)
- **Not flexible at all** (I will not go to activities if they clash w/my bowel management time)

## **BBTI 11**

Hemorrhoids

Sores around the anus

Fissures

Rectal abscess

Rectal prolapse

Anal skin problems

Other

## **BBTI 13**

- Two or more times daily
- Daily
- Not every day but at least once per week
- Not every week but at least once per month
- Less than once per month
- Never
- NA

## **BBTI 15**

Very satisfied

Satisfied

Dissatisfied

Very dissatisfied

## **BBTI 7**

- Two or more times daily
- Daily
- 1-6 times per week
- 3-4 times per month
- Never
- NA (no sensation)

## **BAABBT 1**

- Never (0%)
- Rarely (1 – 20% of the time)
- Sometimes (21 – 69% of the time)
- Often (70 – 99% of the time)
- Always (100% of the time)
- Not Applicable (NA)

## **PROMIS 1**

Excellent

Very Good

Good

Fair

Poor

## **PROMIS 3**

None

Mild

Moderate

Severe

Very severe

## **SCI-QOL 1**

Not at All

A Little Bit

Somewhat

Quite a Bit

Very Much

## **SCI-QOL 2**

Never

Rarely

Sometimes

Frequently

Almost always

## **PROMIS 2**

Never

Rarely

Sometimes

Often

Always

## **QOC**

Very important

Somewhat important

Somewhat unimportant

Very unimportant





## Psychosocial and Behavioral Factors Associated with Bladder and Bowel Management after SCI

Study ID# HUM00068800

Thank you for your participation! Please feel free to contact us anytime at the contact information below with questions or concerns.

Edward J. Rohn, Study Coordinator

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## Your Upcoming Appointment

Your telephone interview will take approximately one hour. Please have the response cards in front of you for your appointment. The telephone interview needs to be within two weeks of your face-to-face interview. Both appointments are listed below.

Face-to-face Interview: \_\_\_\_\_  
Day Date Time Completed?

Telephone Interview: \_\_\_\_\_  
Day Date Time Completed?

Interview Date	/ /
Participant ID	
Interviewer	

## CAREGIVER INTERVIEW GUIDE

**INTRODUCTION:** Thank you for participating in our study. We are interested in learning about your perspective and your experiences providing care to a person with SCI who needs help managing his/her bladder and bowel. We would like for you to be as honest as you can and share your true feelings. We hope that by learning about your experiences and perspectives on caregiving will provide insight into what it is like to care for individuals with neurogenic bowel and bladder and try help others in the future. Be assured that your responses will be treated as confidential. If you need to take a break, let me know and we can stop the interview. Do you have any questions before we get started with the interview? If it is OK with you I would like to **turn on the audio recorder**. Feel free to ask questions as we go along and share additional information that you think might be helpful for us to know about your experiences.

---

**GUIDING CONCEPT FOR INTERVIEWERS:** How has the management of and complications around bowel and bladder issues impacted the PWSCI's quality of life?

How has caring for someone with bowel and bladder complications affected your QOL?  
How has it affected the way you live your life?

**SECTION 1: BACKGROUND INFORMATION:** I would like to begin this interview by asking you to tell me a little bit about the person you care for and how you became (his or her) caregiver?

- 1) Are you the only person providing SCI care to this person?
- 2) [If not a relative] Did you have a prior relationship with the person you are caring for?  
If YES, please describe.

**SECTION 2: SCI CAREGIVER ACTIVITIES:** I would like to know more about you day-to-day caregiving activities. Just briefly describe the tasks you typically do.

- 1) Let's begin with those tasks that you *routinely* perform throughout the day (or during your shift). [ PROBE: If useful, use the caregiver list to guide the conversation]

Caregiving Tasks in the Home
Morning tasks
Afternoon tasks
Evening tasks
Bedtime tasks

**Caregiver Tasks**

- ☐ Feeding
- ☐ Dressing
- ☐ Bathing
- ☐ Bowel care
- ☐ Bladder care
- ☐ Medications
- ☐ Meal prep
- ☐ Laundry
- ☐ Housekeeping

- 1) Are there other caregiving tasks that you routinely do – but not on a daily basis? If so, briefly describe these activities.
- 2) Do you have caregiving responsibilities that take place outside the home (such as medical or therapy appointment)? (If YES, please describe briefly)

**SECTION 3: BOWEL AND BLADDER MANAGEMENT ACTIVITIES:** We interested in learning more about your experiences providing assistance with regard to bowel and bladder management activities.

- 1) What are the various ways you provide assistance with bowel/bladder management activities?

Consider not only “hands on” assistance but any other activities directly or indirectly related to your caregiver role—e.g. laundry, meal planning, administering medications, ordering supplies etc.

- 2) Has the person you care for encountered any major *medical complications* related to neurogenic bladder/bowel that needed treatment and follow-up? If YES, please provide some details, including treatment/follow-up of symptoms?
- 3) Has the person you care for experienced any *emotional distress* associated with SCI that causes you some concern? If YES, provide some details?

Consider the following: anxiety, frustration, depression, resentment, or other behavioral factors that adherence to bowel and bladder regimen.

- 4) How difficult is it for you to do the tasks related to bowel/bladder management? Are there other tasks related to SCI caregiving that are not easy for you to do?

- 5) In your estimation, what things would make your job as a caregiver easier (or more rewarding?)
- 6) To whom do you turn to when you have questions or concerns about the health and welfare of the person you care for? How helpful were the people/agencies you consulted.

Consider *informal resources* (family and friends) and as well as *formal resources* (such as physicians and other health care personal, medical supply houses, and health informational resources).

#### **SECTION 4: Impact of SCI caregiving on family roles and community**

**involvement:** This section focuses more specifically on the impact of SCI caregiving on your family roles and your participation in the community.

1. [If caring for a family member] Has taking on the role of caregiver changed your relationship to the person to whom you provide care? If so, how (or in what way), has your relationship changed? What about your relationship to other family members?
2. Has taking on the role of caregiver changed the nature of your involvement in community-based roles? If so, how has your roles changed?

Consider SCI caregiver's prior roles as employee, student, and/or volunteer roles in the community.

**SECTION 5: SCI CAREGIVER STRESS:** As a caregiver, what are some of the major challenges (stressors) associated with caring for a person with bladder and bowel dysfunction?

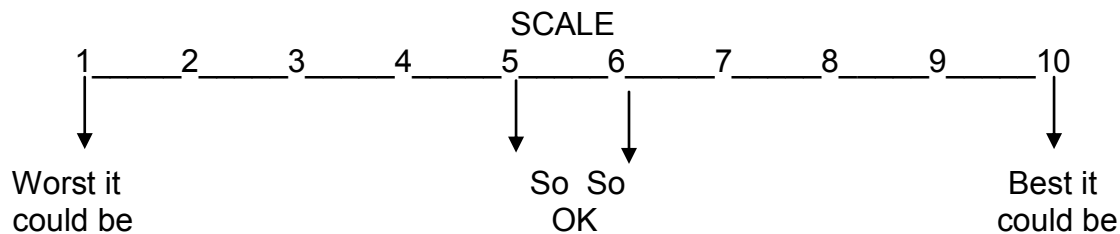
- 1) What do you consider to be the most significant source(s) of caregiver stress? What other issues/situations also cause you a fair amount stress?

Consider the following stressors associated with caregiving: role conflict/role strain; economic issues; medical/behavioral issues affecting the care recipient; health provider issues; other issues.

- 2) What concerns, if any, do you have about the quality of and accessibility of facilities in the community, especially as this relates a person with bladder and bowel dysfunction?

**SECTION 6: LIFE SATISFACTION:** We are approaching the end of the interview. This last section focuses on the impact of your role as caregiver on your own quality of life (or life satisfaction).

- 1) This set of questions has to do with your life *right now* and how satisfied you are with the way your life is going. [SHOW SCALE] On a scale from 1-10 with 1 meaning “worst it could be” and 10 meaning “best it could be” and the middle numbers (5-6) meaning “so-so” or “OK”.



- 2) Do you feel that being a caregiver has had an impact on your physical health? If YES, please describe how caregiving has impacted (either positively or negatively) your physical health?
- 3) Do you feel that being a caregiver has had an impact on your emotional well-being? [If YES, please describe how caregiving has impacted (either positively or negatively) on your emotional wellbeing.
- 4) What, if anything, would improve the quality of your life or enhance your life satisfaction?
- 5) Do you foresee a time in the future when you may *not be* able to continue to provide caregiving services? If so, please describe further.
- 6) Are there any other issues that you would like to comment on?

**\*Thank you very much for your time and interest in participating in our study.**

## Personal Characteristics Form – Caregivers

Gender: ☐ Male ☐ Female

Race: ☐ Caucasian ☐ African American ☐ Asian ☐ Other \_\_\_\_\_

Ethnicity: ☐ Not Hispanic ☐ Hispanic

Current Age: \_\_\_\_\_

Current Marital Status

☐ Single ☐ Married ☐ Significant Other ☐ Divorced  
☐ Separated ☐ Widowed

Highest Level of Education Completed

☐ 8<sup>th</sup> grade or less ☐ 9<sup>th</sup>-11<sup>th</sup> grade ☐ High School or GED  
☐ Associates Degree ☐ Bachelors Degree ☐ Post Graduate Degree  
☐ Other \_\_\_\_\_

Living Situation (Select all that apply)

☐ Live Alone ☐ Live with Spouse/SO ☐ Live with Care Recipient  
☐ Live with Other \_\_\_\_\_

Type of Caregiver: ☐ Family Member

☐ Unpaid family member ☐ Paid family member  
☐ Spouse ☐ Parent ☐ Child ☐ Other \_\_\_\_\_  
☐ Home Health Agency employee ☐ Independent contractor  
☐ Other Paid \_\_\_\_\_ ☐ Other Unpaid \_\_\_\_\_

Do you provide Caregiver Services to more than one person, currently? ☐ Yes ☐ No

(If yes) How many hours per week do you provide Caregiver Services across all of your clients? \_\_\_\_\_ Hours

How long have been providing Caregiver Services to the person discussed during this interview?

\_\_\_\_\_ Years

If you have provided Caregiver Services other than to this person, how long have you been doing this overall?: \_\_\_\_\_ Years

Impairment of Care Recipient: ☐ Paraplegia ☐ Tetraplegia  
☐ Complete ☐ Incomplete

Do you provide assistance with bowel and/or bladder management? ☐ Yes ☐ No

(If caregiver is paid) What is your annual income from serving as a Caregiver?

☐ < \$10,000 ☐ \$10,000 - \$19,999 ☐ \$20,000 - \$34,999 ☐ > \$35,000

What is your annual household income, from all sources?

☐ < \$25,000 ☐ \$25,000 - \$49,999 ☐ \$50,000 - \$74,999 ☐ > \$80,000



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## **Psychosocial and Behavioral Factors Associated with Bladder and Bowel Management after SCI**

### **INTERVIEW COMPENSATION FORM**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Address:

---

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Signature: \_\_\_\_\_

Interviewer: \_\_\_\_\_



### 3. POST INTERVIEW & DATA MANAGEMENT PROCEDURES

1. Following Qualitative Interview
  - a. UM subjects:
    - i. Upload audio file from the digital recorder to the shared drive (DoD Project 2012\Interview Audio Files).
    - ii. Rename file UM-XXX (as appropriate where XXX = assigned Subject ID#).
    - iii. Label analog tape with Subject ID#, date, and tape number (1 of 3, for example).
    - iv. Return all equipment, forms, and analog tape to the Study Coordinator (Rohn).
  - b. VA subjects:
    - i. Upload audio file from the digital recorder to the secure VA drive (TBD).
    - ii. Rename file VA-XXX (as appropriate where XXX = assigned Subject ID#).
    - iii. Label analog tape with Subject ID#, date, and tape number (1 of 3, for example).
    - iv. Return all equipment, forms, and analog tape to secure cabinet in the VA office.
    - v. Study coordinator will periodically sort and file materials at the VA.
2. Following Questionnaire Interview
  - a. UM Subjects:
    - i. All responses should have been entered into REDCap as they are conducted.
    - ii. If this wasn't the case, enter data into appropriate REDCap documents by ID#.
  - b. VA Subjects:
    - i. All responses should have been entered into REDCap as they are conducted.
    - ii. If this wasn't the case, enter data into appropriate REDCap documents by ID#.
3. In all cases, interviewers should coordinate to send a THANK YOU NOTE to the participant. Both the qualitative interviewer and the questionnaire interviewer can sign one note and send it. Notes are available through the study coordinator, and I will leave some at the VA.
4. After all these steps:
  - a. Study coordinator will process a payment with HSIP.
  - b. For UM interviews, study coordinator will upload audio files for transcription.
  - c. For VA interviews, study coordinator will inform approved transcriptionist that files are waiting on the secure VA server.
5. In either case, when the transcripts return, the INTERVIEWER IS RESPONSIBLE FOR READING THE TRANSCRIPT AND CONDUCTING A QUALITY CHECK.
  - a. Study coordinator (Rohn) will contact the interviewer when the transcript returns.
  - b. Check for accuracy, missing/poorly transcribed sections of speak, and overall format.
  - c. When complete, mark in REDCap tracking form that it is complete (TBD).
  - d. Any problems, bring them to the study coordinator (Rohn).

# DoD Project Coding Scheme:

Persons with SCI

**Quality of Life:**  
QOL Reflections  
Subjective QOL Rating

## General Codes:

Aging  
Bladder  
Bowel  
Caregiver  
Good Quote  
Not sure  
Sexuality  
Veteran

**Physical Factors:**  
Health Conditions  
Health Behaviors

**Psychological Factors:**  
Emotional State  
Stress Appraisal  
Coping Strategy

**Social Factors:**  
Social Role Private  
Social Role Public  
Social Support

**Environmental Factors:**  
Physical Environment  
Community Resources  
Financial Resources

**Personal Factors:**  
Demographics  
SCI Experience

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# CODING MANUAL

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Coding Scheme & Instructions 1:

***Persons with SCI***

For the Department of Defense Study:

***Psychosocial and Behavioral Factors Associated  
with Bowel and Bladder Management after SCI***

**CODING SCHEME**

1. ENVIRONMENTAL FACTORS
  - a. Community Resources
  - b. Financial Resources
  - c. Physical Environment

2. GENERAL CODES
  - a. Aging
  - b. Bladder
  - c. Bowel
  - d. Caregiver
  - e. Sexuality
  - f. Good Quote
  - g. Veteran

3. PERSONAL FACTORS
  - a. Demographics
  - b. SCI Experience

4. PHYSICAL FACTORS
  - a. Health Conditions
  - b. Health Behaviors

5. PSYCHOLOGICAL FACTORS
  - a. Emotional State
  - b. Stress Appraisal
  - c. Coping Strategy

6. QUALITY OF LIFE
  - a. QOL Reflections
  - b. Subjective QOL Rating

7. SOCIAL FACTORS
  - a. Social Role Private
  - b. Social Role Public
  - c. Social Support

**DIRECTIONS:** The following code indexing guide is intended to facilitate the coding of narrative text from transcribed interviews. As needed, definitions and / or descriptions are provided. For some coding categories, examples are included to make the coding scheme clearer in its application. Multiple codes can be assigned to any given line or lines of text, as appropriate.

## **ENVIRONMENTAL FACTORS: COMMUNITY RESOURCES**

### **Definition:**

The *social* environment refers specifically to the informal and formal social arrangements through which people conduct their daily life activities. Refers to community agencies/or groups such as

### **Components:**

- a. Medical & health-related goods and services: including goods and services provided by primary care physicians, specialists including PM&R, health care providers, and payors (insurance), case-managers, durable medical equipment and supplies, nursing services, personal care attendant services, and peer support groups, etc.
- b. Community services: including public, commercial and or private transportation services, social services, law enforcement and legal services, and any other public or private goods and services and goods that are not health-related (e.g. restaurants, retail establishments,

### **Common locations:**

### **Examples:**

"The biggest problem that comes up almost all the time is dealing with insurance... the stuff they put you through. You have to get re-certified every week and it just puts so much tension in the air on everybody with the staff here and I don't know why they can't do two-week acceptances at a time. It's kind of crazy that they have to re-certify every week, whether or not I'm making progress. As soon as you stop making progress then the insurance company wants to sweep you out the door...they're just ruthless.... But there's a lot of people involved with... like they'll hit a hiccup here and there and then the other people get involved trying to straighten out the hiccup and dealing with insurance companies is like trying to [herd calves] Can't get the same answer twice in a row from anybody...Yeah, you're getting bills every week for something. When they come and draw blood from you, you can expect another two or three bills. Stuff that should have been sent to the insurance company, they're sending it right to your door. Now you gotta do their job and the insurance company's" (UM-040).

"...just because I have 24-hour nursing, I have the flexibility to go where I want when I want. I have somebody to help me empty my bladder wherever I'm at whenever I need to. It doesn't limit me. If I did not have 24-hour nursing, if I had to have an indwelling catheter or try and plan around people coming and emptying my bladder, life would just be so much more different and restrictive" (UM-020).

"Well you know if I'm going to work I know which bathroom is accessible, easily accessible, has everything I need to use. If you're going out to a restaurant you never know what the restaurant restroom bathrooms are going to be situated like or if you're traveling for business or another facility, you never know what it's going to be like. Sometimes it gets like, you can't shut the door, or you can't even get into the stall. It depends on how the ADA, how generous they were when they set up the building" (VA-002).

**ENVIRONMENTAL FACTORS: FINANCIAL RESOURCES****Definition:**

Includes the following personal income and assets, and monetary resources from health and auto insurance etc.

**Components:**

1. Personal income from work:
2. Insurance payments – health and auto:

**Common locations:****Examples:**

“I’m on short-term disability which will probably turn into long-term disability before long....I turned 61 so I could just go on Social Security as disabled which I guess for me wouldn’t be a bad deal. Along with my retirement benefits and stuff I’d do pretty well....Yeah, if I could just retire and go on Social Security and get the benefits I need to exist on I’d just be fine with that” (UM-040).

“I lived in Michigan. I owned a house in Michigan that was modified. It was beautiful. It was on the water....now I’m in El Paso, Texas. I just have bought a house and we’re in the middle of remodeling to make it accessible for me, but overall, life is really good...Allstate offered to pay for my master’s [MSU] to go back to school.... and the doctorate was there. Michigan State was waiting for me when I was ready and that was paid for. I had to do a TA and a GA and I didn’t make a lot of money, but it was enough to survive” (UM-020).

“I planned on being a career military guy and now I’m data geek at a billion dollar company so, a little different. I still don’t know what I want to be when I grow up. I know that I will still be working; I have a four year old and a nine year old. So retirement’s at least 14, 15 years away so I’ll still be working. We’ve thought about opening our own business or something so we can work together instead of me driving an hour away, but don’t know” (VA-002).

## **ENVIRONMENTAL FACTORS: PHYSICAL ENVIRONMENT**

### **Definition:**

The *physical* environment refers to specifically to the natural environment and the man-made environment (or built) environment. Statements reflecting facilitators or detractors should be coded at this node.

### **Components:**

1. Natural environment: such geography, climate, weather conditions such as snow rain, and temperature.
2. Man-made environment: such as residential dwelling units and surroundings, commercial, civic, and religious structures and surroundings, transportation systems etc.

### **Common locations:**

### **Examples:**

“Yeah, there’s a lot of things....like in my room here I got a refrigerator that’s on the floor under a cabinet – so if I roll up to it and try to open it, I have to roll up to it sideways to open it and then I have to get out of the way of the door...so I can see what’s in it. And then I have to turn around and get as close as I can side-to-side on it so I can reach in and get what I want so that’s rather difficult. And a lot of things get placed just out of my reach” (UM-040).

“My old office had a bathroom....Now what we do is we in my office and then we either empty the urine into a bottle or they just take the bag into the bathroom, empty it and come back and put it back on the back of my chair.

“It’s a bitch to fly, yeah. You’ve got to transfer out of your chair into one of those chairs that they take you onto the plane and then they have to transfer you from that to the airplane seat and back and forth and back and forth. That will break your chair. Being in El Paso, there are almost no direct flights anywhere. We transfer twice. I have to rent a Hoyer and it’s not an electric Hoyer, it’s a hydraulic Hoyer, and I have to rent a van so I have to tie down in that lockdown....I would go where there was a McDonald’s because I knew McDonald’s were guaranteed to have a bathroom that was big enough that I could recline and cath” (UM-020).

“...like when they moved me from the Flint office to the Detroit office I made sure that there was a restroom that was accessible and when they brought me down they told me that if there was anything I needed at the restroom they would modify it, but I didn’t actually need it luckily... I don’t go someplace because I know that they have sand, I avoid those. Wheelchairs and powdered sugar sand don’t go well together, stuff like that or that place is too hilly or what-not....If you’re going out to a restaurant you never know what the restaurant restroom bathrooms are going to be situated like or if you’re traveling for business or another facility, you never know what it’s going to be like. Sometimes it gets like, you can’t shut the door, or you can’t even get into the stall. It depends on how the ADA, how generous they were when they set up the building...My folks when they rebuilt their house made sure they built a special bathroom just for me” (VA-002).

**GENERAL CODES: AGING****Definition:**

Any talk of aging, getting older, or physical changes over time in the body, whether or not it is related to SCI or other health conditions or complications.

**Components:**

1. Related to just getting older
2. Related to health changes from getting older

**Common locations:****Examples:**



## **GENERAL CODES: BLADDER**

### **Definition:**

Any talk or description of the individual's bladder. This can include general reflections, health complications, management, bladder program, etc. In general, this is a code that will help us identify talk around bladder and will often be paired with another code.

### **Components:**

3. Bladder talk – general reflections and the like around their bladder.
4. Bladder health concerns – talk around the medical aspects of neurogenic bladder.
5. Bladder management – talk around the bladder program, supplies, & health behaviors.
6. Bladder problems – talk around how bladder issues interfere with quality of life.
7. Examples: Talk about self cathing, laying down, menstruation and cathing, need a bed to cath. Finding place to cath, self cathing, pain.
8. Key words: bladder, UTI, cath, indwelling cath, intermittent cath, accidents, diapers, pads, bottle, leg bag, suprapubic tube

### **Common locations:**

- SECTION 1: BACKGROUND INFORMATION, Question 2
- SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
- SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

### **Examples:**

“Yeah. It’s interesting because I’ve heard some research that says that given the choice of walking or having your bowel and bladder restored people would actually choose bowel and bladder. To me, it is problematic. It’s something that I’ve learned to live with and accommodate, but it’s certainly one of the top five issues that we have to deal with as an individual with a spinal cord injury. Generally, I’m continent, and I hate to say that because I don’t know that I’ve been incontinent in six or eight months, but as soon as I say that I’m continent, something happens and I have a problem” (UM-020).

“My story of living without bladder and bowel function, I can tell you right now when I was first injured it was actually quite a shock. When you hear about people being paralyzed you don’t realize, well they can’t walk, but you don’t think about all the things that come along with it, bowel, bladder, skin care, all that good, fun stuff. It was very enlightening, let’s put it that way. But I developed a routine, it’s worked well for the bowel. On the bowel side of things it’s, luckily I don’t have a whole lot of digestive problems, so it’s pretty, you know once a day standard routine, it’s no big deal. But the bladder, that’s a pain in the backside because you got to find a restroom where you can do the intermittent catheterization, you got to find a place, you got to find a bathroom that you can use, you got to carry all this stuff around with you to do it. Then you’re always worried, well I am, I don’t know about other people, but if I start coughing or laughing I might you know have a leakage. Then you have the UTI’s that come along with that” (VA-002).

**GENERAL CODES: BOWEL****Definition:**

Any talk or description of the individual's bowel. This can include general reflections, health complications, management, bowel program, etc. In general, this is a code that will help us identify talk around bowel and will often be paired with another code.

**Components:**

1. Bowel talk – general reflections and the like around their bowel.
2. Bowel health concerns – talk around the medical aspects of neurogenic bowel.
3. Bowel management – talk around the bowel program, supplies, and health behaviors.
4. Bowel problems – talk around how bowel issues interfere with quality of life.
5. Key words: digital stimulation, bowel, colostomy, commode chair, accidents, diapers, pads, suppository, constipation, diarrhea

**Common locations:**

- SECTION 1: BACKGROUND INFORMATION, Question 2
- SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
- SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

**Examples:**

"The bowel program is every other night. Every other day in the evening during 9:00. Throughout the years I've had problems with the sluggish bowel, et cetera, and for years my nurses have been telling me, "Why don't we try the warm prune juice at night?" Finally, I agreed and that was about two months ago and that has really changed the quality of my bowel program. It's really made a huge difference" (UM-020).

"Yeah, bowel care, every morning I basically do digital extraction, and that's pretty much it. I don't use any suppositories or anything like that. And so far it's been pretty good. I mean not a whole lot of issues there unless you get the flu, and that's never good. Bladder, I catheterize four times a day, more if I am drinking heavily, but typically four times a day. I wear an external catheter and a leg bag for leakages which works out fine unless you're coughing really hard, and then you have incidences of leakage and whatnot" (VA-002).

**GENERAL CODES: CAREGIVER****Definition:**

Any talk or description of the individual's caregiver. This is a code that will help us identify talk around caregivers and caregiving will often be paired with another code. This code will help us zero in on reflections and experiences with caregivers and caregiving.

**Components:**

1. Caregiver – any mention of the participant's caregiver.
2. Caregiving – any mention of assistance the participant receives related to their SCI or bladder/bowel.

**Common locations:**

- SECTION 1: Background information
- SECTION 2: Bowel and Bladder Program
- SECTION 3: Caregiver/Attendant Relationship
- SECTION 4: Social Relationships, throughout

**Examples:**

"Over the 15 years, 95% of the nurses have been absolutely fabulous—trustworthy, hardworking, honest, have integrity. I manage my own nursing case, so I hire them. That has made a huge difference" (UM-020).

"Yep, they're all doing their jobs and none of them are griping and they're more than willing to help me out with anything I need. If I need something from my room that's out of reach, they'll come and get it for me with no problem" (UM-040).

[Referring to wife as caregiver] "Not anymore, initially she would help me out until I developed strategies or figured out how to do it on my own, but that's been I don't even know how many years now. Same with the bowel program, when I first started, she'd be there helping me, and then I figured out strategies so I could do it independently. Now if for some reason I have a loose, loose stool where it's rather messy, she will come in and help me and make sure I don't spread it over the rest of the house. Yeah, if I need her she comes in and helps out with that stuff, but for the most part, on the average day, she does not get involved" (VA-002).

**GENERAL CODES: GOOD QUOTE****Definition:**

Any talk or response from the participant that is particularly noteworthy, well summarizes the data either within the interview or as an exemplar of broader patterns in the entire dataset, or is particularly poignant and sets this individual statement apart from others. These quotes should be labeled with publications in mind, in that they help demonstrate the specific aims of the project or other key topics to capture around NBB and SCI.

**Components:**

1. Quotes should be identified as important and particularly poignant for the study.
2. Quotes should be coded in a broad way to include context of quote.

**Common locations:**

- Potentially throughout.

**Examples:**

1. (Copy and paste quotes from transcripts)
2. (Add 2-3 examples)

## **GENERAL CODES: SEXUALITY**

### **Definition:**

Any talk, descriptions, or perceptions of sexuality, sexual intimacy, sexual behavior or orientation. This code will help us identify the meaning of sexuality to the participant and may help us determine how sexuality is impacted by neurogenic bladder and bowel.

### **Components:**

1. Sexuality: general perceptions of sexuality, changes since SCI, talk about desires for or avoidance of sexuality
2. Sexual behavior: any mention of physical dimensions of sexuality, barriers to sexual activity, ways sexuality changed since SCI or NBB
3. Physical functioning: ability to engage in sexual behaviors after SCI
4. Sexual intimacy: any mention of sexual relationships, spouse, partner (past or present), dating, discussions of how intimacy has changed since SCI or NBB
5. Sexuality and relationship to caregiver: caregivers may be spouses/partners, identify talk about challenges between caregiver role and romantic partner role
6. Other topics/keywords may include: romance, love, dating, kissing, intercourse, touch

### **Common locations:**

- SECTION 4: Sexuality, social relationships

### **Examples:**

"I was married when I had my injury and since then I have not have any relationships or really thought out any relationship with a man. It's interesting, though. It's hard to say if the spinal cord injury is impacting that because most of my life I've been fairly independent. I've always been working and in school so I've always put relationships on hold because of the other goals that are in my path. I have to say right now I barely have time for friends. I know I don't have time for a relationship. Do I see myself probably five years from now actually making an effort and seeking that out? I'd say yeah, probably, but I've got to be honest and say I think it's going to be difficult. I think it's going to take a certain man, a certain individual to see past the spinal cord injury in order to have a relationship. I don't know. We'll see how that goes. My self-esteem is high. I value myself as a person. I think I'm lovable. I think that if I invest the time, that I will find somebody out there that will love me and we can have a relationship together. But like I said, right now I haven't made it a priority. I'd have to say maybe 30% I'd attribute to spinal cord injury and 70% I would attribute to just too damn busy for a relationship, honestly" UM-020.

"Definitely with the bladder, you have to worry about passing UTI's and all that good stuff. When I was using a Foley when I was first injured you have that whole ugly thing in the way, so that definitely impacts it. It was much more mechanical, more scientific than natural, how's that?" (VA-002)

**GENERAL CODES: VETERAN**

**Definition:**

Any talk of military service or veteran status.

**Components:**

**Common locations:**

**Examples:**

**PERSONAL FACTORS: DEMOGRAPHICS****Definition:**

Demographics will include basic socioeconomic and injury background information about the participant.

**Components:**

Education, age, gender, injury level, research site (UM/VA), time since injury, caregiver (y/n), bladder/bowel program type.

**Common locations:**

- This information will not be content coded in NVivo. This information will be in SPSS/EXCEL. We will create attributes for participants and import the demographic information into NVivo.

**Examples:** n/a

**PERSONAL FACTORS: SCI INJURY EXPERIENCE****Definition:**

This code will be used to identify talk about the SCI injury experience

**Components:**

- Details about the SCI injury (cause, timing in life)

**Common locations:**

- This is discussed in the first question of the interview (“tell me the circumstances surrounding your injury”)

**Examples:**

“I was injured on December 3<sup>rd</sup> of 1997 in a motor vehicle rollover accident. I did my rehab at the University of Michigan Model Spinal Cord Injuries care system. At that time, I had my bachelors in business. Because it was an auto accident, I had a lot of resources and was able to go back to school for my master’s, which I started in probably about 2000.” (UM-20)

“Yeah, I’ve always been heavy into the outdoors and when I was a young child I even did some lumberjack work – I was 13 or so. Anyway, I’ve been around trees all my life – cutting them and stuff and I was trimming a branch in my yard and I had a ladder chained to the tree and I had the [inaudible 0:00:58] tied to the tree and then while I was cutting the tree, the tree... the big limb starts splitting the main trunk. When that happened it broke the chain and when it broke the chain, the chain slidded and it grabbed the ladder and pulled the ladder to the side and it dumped me out of the tree. I landed on my back from about 16 feet up and I broke my back and crushed my spinal cord and broke three ribs on one side and another rib on the other side so I was pretty beat up.” (UM-40)



## **PHYSICAL FACTORS: HEALTH BEHAVIORS**

### **Definition:**

Any description of the individual's actions in managing their own health and wellness, including reducing symptoms, alternative therapies, seeking medical advice, etc. Behaviors taken to treat their neurogenic bladder and/or bowel, past or present, is key. Any description of the individual's actions in terms of addressing or responding to their own health. Focus is on behaviors, conscious or unconscious, that contribute to participant's health and wellness; personal agency managing illness and disease – NBB and managing related complications rather than physical symptoms or the complications themselves (use Health Conditions for this). Further, this is not emotional or psychological coping with NBB (use appropriate Psychological Factor codes for this), but rather actions used in management. Code these management strategies whether the strategy is current or no longer used, significant or minor. These can include personal techniques or daily strategies, physician-recommended or ordered approaches, non-medical treatments, over-the-counter remedies, holistic medicine.

### **Components:**

1. Bladder management: includes description of bladder program, use of catheters, decisions of when and how to cath, routines, strategies for preventing or responding to accidents.
2. Bowel management: includes description of bowel program, materials used for bowel program, routines, and strategies for preventing or responding to accidents.
3. Illness management: includes strategies and recommendations for managing or treating other diseases or illnesses
4. Recommendations: includes recommended courses of action/treatment from physicians or other sources.

### **Common locations:**

1. SECTION 1: BACKGROUND INFORMATION, Question 2
2. SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
3. SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions
4. SECTION 3: RELATIONSHIP WITH DOCTOR/HEALTH CARE PROVIDERS, all questions

### **Examples:**

"But generally, both my bladder and bowel are very, very stable so I really don't have issues. I do have 24-hour nursing, so I have a nurse that travels with me and I do intermittent catheterization every two to three hours as needed, and then the bowel program every other night" (UM-020).

"But it was there all the time and they would change me from a leg bag to a night bag when I went to bed at night. And my volumes have been fairly high I guess as far as that goes but trying to get me to drink less fluids and also trying to get me to lose some weight so that I can handle my weight a little better as far as transfers to" (UM-040).

**PHYSICAL FACTORS: HEALTH CONDITIONS****Definition:**

Any description of the individual's medical or health-related conditions, diseases, diagnoses, complications, etc. These can be related to or resulting from neurogenic bladder and/or bowel, past or present, but should be double-coded with "bladder" or "bowel" as appropriate. Focus is on physical symptoms and disease rather than personal agency and health behaviors (use Health Behaviors code for this). Code whether the disease, diagnosis, or complication is current or resolved, significant, minor, or no impact. These can include personal recalled experiences (that may not include a medical label or diagnosis) or formal medical diagnoses.

**Components:**

1. Diseases and medical conditions: this can include bladder/bowel, injuries, comorbidities, other medical symptoms and circumstances.
2. Complications: Complications or symptoms resulting from any medical condition. For NBB this includes UTIs, kidney or bladder stones/infections, leakage, incontinence, pain related to urinary system or urinating, sores from cathing. Hemorrhoids, constipation, incontinence, bloating, pain related to bowels or having a bowel movement, skin infections, sores.

**Common locations:**

1. SECTION 1: BACKGROUND INFORMATION, Question 2
2. SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
3. SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

**Examples:**

"Bowel accidents, I think in the 20 years I think I've had two. I've been very lucky on the bowel side. The bladder on the other hand, that's a constant, especially when I get allergies and start sneezing and coughing and you're always wondering, did it slip off or can anybody smell that? Yeah" (VA-002).

## **PSYCHOLOGICAL FACTORS: COPING STRATEGY**

### **Definition:**

Refers to a cognitive, emotional, and/or behavioral effort directed at managing, reducing, or tolerating the internal and/or external demands of life. The coping effort may or may not be successful and in some cases may have negative effects (e.g. drinking alcohol to manage anxiety). The individual may be more or less aware of using a particular strategy for dealing with a stressor or life circumstance. Coping strategies are not mutually exclusive, although an individual may rely more heavily on a particular style of coping. General or global references to coping or needing to cope that cannot be coded in accordance with the specific categories below should be coded at the parent node.

### **Components:**

1. **Emotion-Focused**: Attempts to cope that are either directly or indirectly focused on managing, manipulating, and/or regulating one's emotional experience in life. Such coping efforts may include strongly cognitive or behavioral elements despite the emphasis on emotional experience. This would include attempts to view an event in a new light such as by "looking for the silver lining" or making comparisons about how "things could be worse." Other examples of emotion-focused coping include: directly expressing feelings to others for purposes of emotion-processing, withdrawing from others to avoid certain feeling states, avoiding talking about feelings, suppressing thinking about a situation or alternatively trying to think it through in order to feel differently about it, engaging in wishful thinking, daydreaming or fantasizing, using sedatives (food, medicine, or alcohol), distracting the self or otherwise achieving emotional distance from a situation such as through intellectual denial or emotional detachment, looking for the humor in life, and the use of calming or relaxation techniques.
2. **Problem-Focused**: Attempts to solve or somehow resolve a situation, either directly or indirectly, by initiating some type of action or intervention that is aimed at alleviating or remedying the situation. This includes chunking elements of a problem or breaking a problem down into manageable pieces, seeking information, considering alternatives, and direct action. This might also include delaying a decision or action until more information is available or suppressing action to avoid making the problem worse.
3. **Social Support-Focused**: Attempts to find help in coping with life or a situation by asking for advice, concrete aid, emotional support, affirmation of perceptions, positive regard of actions taken, or other form of social support. The nature of the social support sought may be either formal (e.g., attending a support group) or informal (e.g., talking with friends).
4. **Meaning-Focused**: Attempts to create or find meaning in one's life experience through reference to a higher being or in reference to the larger scheme of things. This includes the use of an overarching meaning system based on religious, spiritual, or philosophical beliefs and values to change one's image of nature, body, self, society, and culture. Concrete strategies include but are not limited to activities such as engaging in prayer, reading the bible, meditation, and participation in rituals. Some commonly reported coping strategies include the following: "going to church," "drawing strength from

adversity," "growing as a person," "rediscovering what is important," "feeling transformed," "taking strength from God," "finding new faith," "reading inspirational stories," "listening to faith-based programs," an so on.

**Common locations:**

Throughout interview.

**Examples:**

"I had these really humiliating moments where we would cath and I'd come out and there would be bag of urine stuck to my leg because we forgot to empty it as I flew out of the bathroom. And then I realized it can kill me, right? Life goes on. So sometimes you deal with these embarrassments and you realize that it's a part of being human and that it didn't kill you and maybe those kinds of things. Like Nietzsche says, "What doesn't kill you makes you stronger." It could have been a little bit of that, too, having to face the reality that shit happens" (UM-020)

"Beatrice Wright talked about that, shifting what's important to you and what you value, so I find other things to do at night."

"I've always been very optimistic and things that would bug people and bring them down never bothered me as much. Like the therapist said, I don't think you're going to get depressed. That's not going to do me any good, I'm still going to be, getting depressed is still going to leave me here in the chair. I don't know, I guess I just always faced life with it's what you got. You only get one shot. And make the best with whatever I got. "

## **PSYCHOLOGICAL FACTORS: EMOTIONAL STATE**

### **Definition:**

Any description of the individual's emotional state, past or present. Code emotional content regardless whether it is positive, negative, or neutral. Use to describe emotional states rather than psychiatric diagnoses in the cases of depression and anxiety.

### **Components:**

1. Depression: Includes any discussion of feeling hopeless, helpless, sad/gloomy/dejected, inability to enjoy life, apathy, emotionally withdrawal, isolated/lonely(regardless of actual social environment).
2. Anger: frustration, resentment, hostility, fury, aggravation.
3. Anxiety: insecurity, vulnerability, concern, nervousness, worry, fear, terror.
4. Surprise/Shock: can range from mild surprise to disgust, horror, repulsion.
5. Stress/Overwhelmed: the emotional aspects of perceived demands exceeding personal capacity. Feeling overcome, overwhelmed, overloaded, crushed by the weight of demands.
6. Grief/Loss: sadness and grief specific to a loss event (may be linked to text that is coded as a Loss Stress Appraisal).
7. Social emotions: emotions in regard to another person or persons – embarrassment, stigma, guilt, love, hate, fondness, connection, companionship, protectiveness (as in taking care of children)
8. Happiness/Joy: positive emotions ranging from contentment/fulfillment/amusement to euphoria.
9. Optimism/Excitement/Hope: future-oriented positive emotions.
10. Gratitude: thankfulness, appreciation
11. Calm: Serenity, peacefulness, relaxed
12. Resilience/Confidence/Self-Efficacy: feelings of strength, adequacy, or of being able to “come back from” “bounce back from” or recover emotionally from difficulty.

### **Common locations:**

Throughout the interview

### **Examples:**

“It’s funny because when I was first year post injury, we were not allowed to use the word *catheterization*. We called it *the C thing*. I was just really embarrassed. I didn’t want anybody to know so it was something that I kept very hidden and very private.”

“The thing is I’m happy with my life.”

“I can tell you right now when I was first injured it was actually quite a shock.”

“Then you’re always worried, well I am, I don’t know about other people, but if I start coughing or laughing I might you know have a leakage.”

**PSYCHOLOGICAL FACTORS: STRESS APPRAISAL****Definition:**

The perception that a situation exceeds or may exceed resources and capacity (internal or external) in terms of functioning, adaptation, or coping.

**Components:**

1. **Challenge:** An appraisal of an event, situation, or life circumstance that may be on the part of the individual. Challenges are more likely to be viewed as “controllable” and may be viewed as having a positive component (“good stress”). Some common challenges are associated with life transitions, such as getting married, childbirth, moving to a new locale, starting school or a new job, etc. Other challenges may be more directly related to the SCI, such as involving the carrying out of activities of daily living or arranging for transportation. Some challenges may evoke excitement or either positive or negative tone but as requiring unusual or exceptional effort eagerness, while other may evoke some degree of annoyance, anxiety, or self-doubt. Even if a challenge is perceived as exceptional and/or as having potential significant consequence for the individual, it is not viewed by the individual as posing a real or significant threat to physical or emotional well-being. In this sense, what is a challenge or threat is defined by the individual in that the same stressor might be viewed, alternately, as either a challenge or a threat depending upon personal or contextual factors.
2. **Threat:** Damage that is anticipated and may or may not be inevitable. Threats may be accompanied by strong negative emotions such as anger, fear, and resentment. Some examples of threats are worries about future health and functioning, aging, finances, a loved one experiencing difficulty, etc.
3. **Loss:** Damage that has already occurred, such as the death of a spouse, friend, or pet or an accidental injury that is accompanied by permanent functional losses. Loss could also refer to such situations as loss of a home or damage to a friendship.

**Common locations:**

Throughout interview.

**Examples:**

“It’s a pain, but you learn to adjust to it. To me it’s more stress. When I’m under a lot of stress, which I’m under a lot of stress right now, that keeps me awake more than the bowel/bladder issue...It’s all work. Work and the good stuff, buying the house and getting the house remodeled. But mainly it’s just so much work. And then we’ve got our core accreditation audit coming. I’m hiring two faculty, I’m starting a lab. All of that stuff that comes with running a department and just learning it all.”

“The stress, the loads of stress, especially when you pay bills and they re-bill you for the same bill and then you gotta go back and call them and straighten them out. It’s just insane. “

## **QUALITY OF LIFE: QOL REFLECTIONS**

### **Definition:**

SCI-Health-related life satisfaction refers to aspects of a person's overall well-being that can be clearly shown to affect and/or be affected by the presence of an SCI impairment and/or by past and current health status (physical, mental, or social). Life satisfaction (subjective QOL) refers to the individual's response to the "goodness of fit" between expectations and achievements, as experienced by the person, within a time perspective.

### **Components:**

1. Expectations: is a label for the broad category of what should be goals, values, standards of comparison, desires, aspirations, wants and needs, etc.
2. Achievements: refers to what the person actually has, is, or controls, such as performances, accomplishments, possessions, relationships, etc. These achievements are held up to the expectations listed above
3. Emotional and/or cognitive response: The individual's assessment of the congruence or gap between his or her expectations and achievements e.g.:
  - a. Happiness or sadness
  - b. Satisfaction/ dissatisfaction
  - c. Zest for life/depression
  - d. positive/negative affect

### **Common locations:**

- Section 4: Life course expectations
- Potentially throughout interview

### **Examples:**

"I expect all that stuff to come back. That's my beliefs and my expectations for myself so I'm not letting it worry me right now. I hope that I can get home and I can control that stuff so my wife doesn't have to deal with But it's just gonna take time. I'd like to be fully restored and retired and have time to go up north and enjoy my cabin and my property up there and go do the things I always wanted to do. Life in a wheelchair is rather difficult....[SCI] ....it hasn't beat me up at all; hasn't changed me a bit... I have to deal with it; we just make light of it and laugh about it here and there and it's... you just take care of business and get on with it" (UM-040).

"I've achieved everything that I wanted to achieve in my life and more. I've actually exceeded my expectations of what I thought my life would be. And to be honest with you, had I not had the spinal cord injury I don't know that I would be saying that. So I can really attribute where I'm at to the acquisition of my spinal cord injury" (UM-020).

"Well I never thought I'd be sticking a catheter into my bladder four times a day. I never thought I'd be sticking a finger up my bum every day either, but those are the realities of life now. I don't know if, they've just redefined, I don't think they've changed my professional, my spinal cord injury altogether changed my life goals. I planned on being a career military guy and now I'm data geek at a billion dollar company so, a little different" (VA-002).

**QUALITY OF LIFE: SUBJECTIVE QOL RATING****Definition:**

This code refers to the specific question on Quality of Life that appears at the end of the interview and includes a numerical score.

**Components:**

1. Numerical score on QOL (1-10) rating scale
2. Reasons for numerical rating of QOL

**Common locations:**

- Section 4: Life course expectations

**Examples:**

“Probably about a 7. Well I’m totally comfortable here at this facility. All the people are very good. They do their services to the people that are here pretty much on timely schedules and within an acceptable range of... as far as doing a complete job and on time. The facility here is just beautiful. People walk into my room; they can’t believe how nice it is. All the furniture appointments and everything are really nice. I’ve got two recliner chairs in my room and a mechanical bed; TV with a real nice entertainment center and just about everything you could want for yourself. It’s got a kitchen kind of thing. It doesn’t have stoves in it but it’s set up to actually take a microwave. As far as here, getting around, doing whatever you want to do has been real good and the people make it easier for you. They often will, if you’re sitting in the hall or something, they ask you if there’s something they can do for you” (UM-040).

“I’ve got to give myself somewhere between a nine and a ten. I’m going to pick a nine because there’s always room for improvement, but I would pick a nine because I’m totally empowered; I love what I do. I teach, I do research, I’m totally independent socio-economically and I’m pretty solid. My needs are met. I have pretty much everything that I wanted” (UM-020).

“Let’s see, if I won the lottery last night it would be a ten. I still have a job so it’s not a one. Probably an eight or nine...because for the most part I’m pretty happy with the way my life is. Could it be better? I’m sure it could. I have a good job, I have a good wife, my kids are healthy, fairly intelligent, not killing each other yet. So yeah, for the most part life’s pretty darn good. Could it be better? Sure, I could wake up tomorrow and have full bowel and bladder control. Not going to happen, but I could win the lottery. That’d be nice. My boss could wake up tomorrow and go, hey let’s make you a, give you a promotion or give you a pay raise. Things could always be better” (VA-002).



**SOCIAL FACTORS: SOCIAL ROLE PRIVATE****Definition:**

This code should be used for any talk around a person's role, relationship, or interaction with spouse/partner, children, family, caregiver and friends – in general, those with whom the participant has a direct, personal relationship; people that form part of his/her immediate personal-social network.

**Components:**

1. General: perceptions of private life, expectations, roles, relationships, interactions with
2. Roles: spouse/romantic partner, parent, grandparent, family member, friend, care recipient

**Common locations:**

1. Section 4: Social relationships
2. Throughout the transcript

**Examples:**

"I would say that it's of course at differing levels. Let's start with family. Family, it hasn't really impacted at all as far as the relationships go. A couple of my sisters know how to cath me and are comfortable cathing me. It has impacted when I travel. Instead of being able to go and stay at one of my sisters' houses, I have to stay at a hotel because I have the nurses. Could I stay at their house? Probably, but access would be a problem, having the nurses there, so that's an issue there. Friends are cool. It's kind of weird because I'm always traveling with my nurse so I have a third person, but usually what happens is if I go out to the restaurant or the movies, the nurse will just drop me off and then come back and pick me up. I just text her, so then I am able to do a one-on-one with my friends because I don't drive" (UM-020).

"Travel is a pain. I don't travel unless I absolutely have to. So that has really probably impacted my relationships with my family and friends in Michigan, Florida. If I didn't have the spinal cord injury I would probably be flying out five, six times a year visiting people. I just realized I went home for a family reunion in September and it was the first time I'd been home since I left Michigan" (UM-020).

**SOCIAL FACTORS: SOCIAL ROLE PUBLIC****Definition:**

This code should be used for any talk around a person's role, relationship, interaction, or perceptions of life outside of the home including work, community, or volunteering – in general, those with whom the participant has a more formal relationship outside their immediate personal network.

**Components:**

1. Work: relationships with coworkers, job responsibilities, career
2. Community:
3. Volunteer:

**Common locations:**

1. Section 4: Social relationships
2. Throughout the transcript

**Examples:**

"Oh, absolutely. It's never a question. I pretty much am able to plan my own schedule and I work pretty independently so I don't have a lot of situations where I'm running into a problem. But I'm fine telling people, "I'm sorry, I need a ten-minute break to use the bathroom," and they're fine with that, too" (UM-020).

**SOCIAL FACTORS: SOCIAL SUPPORT****Definition:**

This code should be used for any talk around perceptions and discussions related to support or lack of support provided by others (family, friends, community, caregiver).

**Components:**

1. Friends
2. Family
3. Spouse (may often be double-coded with caregiver)

**Common locations:**

1. Section 4: Social relationships
2. Throughout the transcript

**Examples:**

# DoD Project Coding Scheme:

Caregivers

## Quality of Life:

QOL Reflections  
Subjective QOL Rating

## General Codes:

Aging  
Bladder  
Bowel  
Person with SCI  
Sexuality  
The Job  
Veteran

Good Quote  
Not Sure

## Physical Factors:

Health Conditions  
Health Behaviors

## Psychological Factors:

Emotional State  
Stress Appraisal  
Coping Strategy

## Social Factors:

Client/Caregiver  
Relationship  
Social Role Private  
Social Role Public  
Social Support

## Environmental Factors:

Physical Environment  
Community Resources  
Financial Resources

## Personal Factors:

Demographics  
SCI Experience

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# CODING MANUAL

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Coding Scheme & Instructions 2:

***Caregivers***

For the Department of Defense Study:

***Psychosocial and Behavioral Factors Associated  
with Bowel and Bladder Management after SCI***

**CODING SCHEME**

1. ENVIRONMENTAL FACTORS
  - a. Community Resources
  - b. Financial Resources
  - c. Physical Environment

2. GENERAL CODES
  - a. Aging
  - b. Bladder
  - c. Bowel
  - d. Person with SCI
  - e. Sexuality
  - f. The Job
  - g. Veteran
  - h. Good Quote
  - i. Not Sure

3. PERSONAL FACTORS
  - a. Demographics
  - b. SCI Experience

4. PHYSICAL FACTORS
  - a. Health Conditions
  - b. Health Behaviors

5. PSYCHOLOGICAL FACTORS
  - a. Emotional State
  - b. Stress Appraisal
  - c. Coping Strategy

6. QUALITY OF LIFE
  - a. QOL Reflections
  - b. Subjective QOL Rating

7. SOCIAL FACTORS
  - a. ClientCaregiver Relationship
  - b. Social Role Private
  - c. Social Role Public
  - d. Social Support

**DIRECTIONS:** The following code indexing guide is intended to facilitate the coding of narrative text from transcribed interviews. As needed, definitions and / or descriptions are provided. For some coding categories, examples are included to make the coding scheme clearer in its application. Multiple codes can be assigned to any given line or lines of text, as appropriate.

**ENVIRONMENTAL FACTORS: COMMUNITY RESOURCES****Definition:**

Refers to community agencies/or groups that provide job or organizational support. Would include community resources that caregiver uses to help care for person with SCI, or that caregiver discusses in relation to person with SCI

**Components:**

- a. Medical & health-related goods and services: including goods and services provided by primary care physicians, specialists including PM&R, health care providers, and payors (insurance), case-managers, durable medical equipment and supplies, nursing services, and peer support groups, etc. Description of health agency that caregiver is employed by, or supervisors who answer medical or care questions. May be double coded with "Job"
- b. Community services: including public, commercial and or private transportation services, social services, law enforcement and legal services, and any other public or private goods and services and goods that are not health-related (e.g. restaurants, retail establishments,

**Common locations:****Examples:**

We have a supervisor that is in charge of his case. I think she's a case manager. She's with Arcadia and if I have any problems I'll call and talk with her. If there are questions or concerns a lot of the nurses will discuss that among ourselves and if it's something we can't solve or we need more help then we'll go to the supervisor, but we try to problem solve on our own as much as we can. But if there are any problems or concerns I'll speak with the case worker and if I need to I'll speak with his doctor because he's got a primary physician that's in Charlotte that we can speak with (UM-101).

**ENVIRONMENTAL FACTORS: FINANCIAL RESOURCES****Definition:**

Includes the following personal income and assets, and monetary resources from health and auto insurance etc. Any description of Person with SCI finances is double coded with "Person with SCI".

**Components:**

1. Personal income from work: Any description of payment.
2. Insurance payments – health and auto: Any description of benefits or lack thereof

**Common locations:****Examples:**

I do feel medical benefits with agencies are lacking. They're seriously lacking. If the caregivers through the agencies had – like if you work for the state you've got an awesome medical benefits package that you get. Or if you're a fulltime firefighter, police officer, a nurse in a hospital, you've got these nice medical packages for people. Home health agencies, we don't have that. That would be a bonus; if we actually had our employers with the agencies offer us medical benefits that they put a portion in as well as our own portion (UM-101).

And caregivers are constantly paid late by the state of Michigan. I recognized that when I was paid by the state and my uncle whenever I would do an hour or two for him he would say, "Did you get your check?" It was only like \$20 or whatever so I'm not really looking for the check, I do it because I love him you know what I mean? But he was like, "Well, John [01:04:12] didn't get his check." But that's John's [01:04:15] source of income. It comes once a month and its \$1,000 or \$2,000 or whatever it is. And it's like, I have asked my teachers in school because they're rehab counselors and they do all this advocacy in legislation, when are people going to fight for the rights of caregivers? There's no medical insurance, there's no living wage, but then I think if people see the importance of caregivers like for example with my uncle being turned often, then he doesn't have to be hospitalized (VA-102).



**ENVIRONMENTAL FACTORS: PHYSICAL ENVIRONMENT****Definition:**

The *physical* environment refers specifically to the natural environment and the man-made environment (or built) environment. Statements reflecting facilitators or detractors for persons with SCI should be coded at this node. Statements reflecting physical work environment should also be coded at this node.

**Components:**

1. Natural environment: geography, climate, weather conditions such as snow ,rain, and temperature.
2. Man-made environment: such as residential dwelling units and surroundings, commercial, civic, and religious structures and surroundings, transportation systems etc.

**Common locations:****Examples:**

The only place that is impossible for us to go is anywhere like to the beach or if we want to go out to the pier, up to the lighthouses, that's impossible; that doesn't happen. Wheelchairs are just not made for that (UM-102).

**GENERAL CODES: AGING****Definition:**

Any talk of aging, getting older, or physical changes over time in the body,.

**Components:**

1. Related to just getting older
2. Related to health changes from getting older
3. Related to person with SCI getting older (Double coded with Persons with SCI)

**Common locations:****Examples:**

Yeah, not in the near future. As I get older I think some of the physical aspects of the job might slow me down. I might not be able to do as much with him, but if I stay healthy and keep exercising I think I'll be able to do it for a while. I mean I see in the future, the older I get the more difficult it may be on me to do a lot of the work he requires, but that's not in the near future (UM 101).

**GENERAL CODES: BLADDER****Definition:**

Any talk or description of the person with SCI's bladder. This can include general reflections, health complications, management, bladder program, etc. In general, this is a code that will help us identify talk around bladder and will often be paired with another code, especially "the Job".

**Components:**

4. Bladder talk – general reflections and the like around their bladder.
5. Bladder health concerns – talk around the medical aspects of neurogenic bladder.
6. Bladder management – talk around the bladder program, supplies, & health behaviors.
7. Bladder problems – talk around how bladder issues interfere with quality of life.
8. Examples: Talk about self cathing, laying down, menstruation and cathing, need a bed to cath. Finding place to cath, self cathing, pain.
9. Key words: bladder, UTI, cath, indwelling cath, intermittent cath, accidents, diapers, pads, bottle, leg bag, suprapubic tube

**Common locations:****Examples:**

That would be the only stress. Her bladder is pretty well, I guess I'd call it trained cause when you put a cath in it goes and then she doesn't have accidents with her bladder at all so there's no stress there (UM 102).

Oh, yeah, every three hours I do a cath. That's very important. I do a straight cath on him about every three hours for his bladder. He only has a Foley in at night when he's sleeping, other than that we do straight cathing (UM 101).

Yeah but I think the more prominent issue is the bladder and the bowel (VA 102).

**GENERAL CODES: BOWEL****Definition:**

Any talk or description of the Person with SCI's bowel. This can include general reflections, health complications, management, bowel program, etc. In general, this is a code that will help us identify talk around bowel and will often be paired with another code.

**Components:**

1. Bowel talk – general reflections and the like around their bowel.
2. Bowel health concerns – talk around the medical aspects of neurogenic bowel.
3. Bowel management – talk around the bowel program, supplies, and health behaviors.
4. Bowel problems – talk around how bowel issues interfere with quality of life.
5. Key words: digital stimulation, bowel, colostomy, commode chair, accidents, diapers, pads, suppository, constipation, diarrhea

**Common locations:****Examples:**

Yeah. And then like say if there is a situation where his bowel care really frustrates him sometimes. For the most part he's able to evacuate mostly sitting on the toilet. But then say if he's sick and he has diarrhea or if he's constipated or you know, I do usually have to empty him some at the end of his program. And I also have to always make sure that the suppository has been removed because if you leave the residue from the suppository in there then you're like setting him up for a bowel accident later in the day. But if it's a difficult bowel day because of whatever, maybe he ate the wrong thing or he's feeling ill then he gets really frustrated. (VA-102).

Yeah, after we do supper I give him a prune. He gets a prune every night. It helps with his bowel program. He gets a prune at night and then I just wait for the night shift and they don't get there until 7:00 (UM-102).

**GENERAL CODES: PERSON WITH SCI****Definition:**

Any talk or description of the individual's caregiver. This is a code that will help us identify talk around caregivers and caregiving will often be paired with another code. This code will help us zero in on reflections and experiences with caregivers and caregiving.

**Components:**

1. Caregiver – any mention of the participant's caregiver.
2. Caregiving – any mention of assistance the participant receives related to their SCI or bladder/bowel.

**Common locations:**

- SECTION 1: Background information
- SECTION 2: Bowel and Bladder Program
- SECTION 3: Caregiver/Attendant Relationship
- SECTION 4: Social Relationships, throughout

**Examples:**

"Over the 15 years, 95% of the nurses have been absolutely fabulous—trustworthy, hardworking, honest, have integrity. I manage my own nursing case, so I hire them. That has made a huge difference" (UM-020).

"Yep, they're all doing their jobs and none of them are griping and they're more than willing to help me out with anything I need. If I need something from my room that's out of reach, they'll come and get it for me with no problem" (UM-040).

[Referring to wife as caregiver] "Not anymore, initially she would help me out until I developed strategies or figured out how to do it on my own, but that's been I don't even know how many years now. Same with the bowel program, when I first started, she'd be there helping me, and then I figured out strategies so I could do it independently. Now if for some reason I have a loose, loose stool where it's rather messy, she will come in and help me and make sure I don't spread it over the rest of the house. Yeah, if I need her she comes in and helps out with that stuff, but for the most part, on the average day, she does not get involved" (VA-002).

**GENERAL CODES: GOOD QUOTE****Definition:**

Any talk or response from the participant that is particularly noteworthy, well summarizes the data either within the interview or as an exemplar of broader patterns in the entire dataset, or is particularly poignant and sets this individual statement apart from others. These quotes should be labeled with publications in mind, in that they help demonstrate the specific aims of the project or other key topics to capture around NBB and SCI.

**Components:**

1. Quotes should be identified as important and particularly poignant for the study.
2. Quotes should be coded in a broad way to include context of quote.

**Common locations:**

- Potentially throughout.

**Examples:**

1. (Copy and paste quotes from transcripts)
2. (Add 2-3 examples)

**GENERAL CODES: SEXUALITY****Definition:**

Any talk, descriptions, or perceptions of person with SCI's sexuality, sexual intimacy, sexual behavior or orientation as described by the caregiver . This code will help us identify the meaning of sexuality to the participant and may help us determine how sexuality is impacted by neurogenic bladder and bowel. Also code any talk of caregiver who is spouse or partner about their own personal sexuality, sexual intimacy, sexual behavior or orientation as it relates to the person with SCI.

**Components:**

1. Sexuality: general perceptions of sexuality, changes since SCI, talk about desires for or avoidance of sexuality
2. Sexual behavior: any mention of physical dimensions of sexuality, barriers to sexual activity, ways sexuality changed since SCI or NBB
3. Physical functioning: ability to engage in sexual behaviors after SCI
4. Sexual intimacy: any mention of sexual relationships, spouse, partner (past or present), dating, discussions of how intimacy has changed since SCI or NBB
5. Sexuality and relationship to caregiver: caregivers may be spouses/partners, identify talk about challenges between caregiver role and romantic partner role
6. Other topics/keywords may include: romance, love, dating, kissing, intercourse, touch

**Common locations:**

- 

**Examples:**

Then he asked me, "Well how do you feel about him having a caregiver?" I said, "I don't care. I don't mind because I've been doing this line of work. I know that when I see you naked there's nothing sexual to it, I'm not hot. There's nothing to it. I don't even realize that you're naked. I'm just talking to you and we're just doing our thing so I would think that's someone who is doing this line of work wouldn't think anything about it." But I could see how someone who has not ever been a caregiver themselves may feel uncomfortable about having someone come in to care for their husband or their spouse or whatever (VA-102).

**GENERAL CODES: VETERAN****Definition:**

Any talk from caregiver about their own military service or veteran status or about their client's military background.

**Components:** 1. Any discussion of military service  
2. Any talk of using veteran services

**Common locations:****Examples:**

So when we go to a PVA function, paralyzed veterans functions of course they're cognizant of having the appropriate spacing.



**PERSONAL FACTORS: DEMOGRAPHICS****Definition:**

Demographics will include basic socioeconomic and background information about the caregiver

**Components:**

Education, age, gender, injury level, research site (UM/VA), time since injury, caregiver (y/n), bladder/bowel program type.

**Common locations:**

- This information will not be content coded in NVivo. This information will be in SPSS/EXCEL. We will create attributes for participants and import the demographic information into NVivo.

**Examples:** n/a

**PERSONAL FACTORS: SCI INJURY EXPERIENCE****Definition:**

This code will be used to identify talk about the SCI injury experience from the caregivers perspective

**Components:**

- Details about the SCI injury (cause, timing in life)

**Common locations:****Examples:**

## **PHYSICAL FACTORS: HEALTH BEHAVIORS**

### **Definition:**

Any description of the caregiver's actions in managing their own health and wellness or the person with SCI's health and wellness (double coded as "person with SCI"), including reducing symptoms, alternative therapies, seeking medical advice, etc. Behaviors taken to treat person with SCI's neurogenic bladder and/or bowel, past or present, is key. Any description of the individual's actions in terms of addressing or responding to their own health. Focus is on behaviors, conscious or unconscious, that contribute to participant's health and wellness; personal agency managing illness and- managing related complications rather than physical symptoms or the complications themselves (use Health Conditions for this). Further, this is not emotional or psychological coping (use appropriate Psychological Factor codes for this), but rather actions used in management. Code these management strategies whether the strategy is current or no longer used, significant or minor. These can include personal techniques or daily strategies, physician-recommended or ordered approaches, non-medical treatments, over-the-counter remedies, holistic medicine.

### **Components:**

1. Management of Person with SCI's bladder: includes description of bladder program, use of catheters, decisions of when and how to cath, routines, strategies for preventing or responding to accidents.
2. Management of Person with SCI's bowel: includes description of bowel program, materials used for bowel program, routines, and strategies for preventing or responding to accidents.
3. Illness management: includes strategies and recommendations for managing or treating other diseases or illnesses
4. Recommendations: includes recommended courses of action/treatment from physicians or other sources.

### **Common locations:**

### **Examples:**

So I go to bed about 4 o'clock, 5 o'clock every morning and Maurice [00:50:57] is up at 7:30 or 8. When he was working he was up at 5. So you're talking about, I get maybe 2 hours of sleep. It takes maybe 2.5 to 3.5 hours, depending on what we're doing, to get him dressed in the morning. So if he gets up at 8 let's say he's done by 11 or 11:30, maybe 12 at the latest. And then I have to leave [Ann Arbor 00:51:17] at 1 to go to school. So then usually what I try to do is hurry up and get him dressed in the morning and get everything set and then get back in bed for that 1 or 2 hours. So not getting enough sleep, there's been times where I, I guess that would be a source of frustration at times because it's not really his disability, but maybe my disability of the sleep disorder (VA 102).

### **DOUBLE CODE AS "PERSON WITH SCI"**

Yeah, sometimes he could successfully do it on his own but he, like I said, he was so weak. And I also think where somebody's point of injury is, how much balance they have would have to do

with how they could actually accomplish it physically at first. I actually did the program for him manually. I did the, you know, the cleaning out. I don't know the proper terms even for it (VA 106).

**PHYSICAL FACTORS: HEALTH CONDITIONS****Definition:**

Any description of the individual's medical or health-related conditions, diseases, diagnoses, complications, etc. Also, any description of Person with SCI's health related conditions as described by the caregiver. Focus is on physical symptoms and disease rather than personal agency and health behaviors (use Health Behaviors code for this). Code whether the disease, diagnosis, or complication is current or resolved, significant, minor, or no impact. These can include personal recalled experiences (that may not include a medical label or diagnosis) or formal medical diagnoses.

**Components:**

1. Diseases and medical conditions: this can include any medical symptoms and circumstances for the caregiver or for the person with SCI described by the caregiver.
2. Complications: Complications or symptoms resulting from any medical condition. For caregiver's describing Patient's with SCI's experience with NBB this includes UTIs, kidney or bladder stones/infections, leakage, incontinence, pain related to urinary system or urinating, sores from cathing. Hemorrhoids, constipation, incontinence, bloating, pain related to bowels or having a bowel movement, skin infections, sores.

**Common locations:****Examples:**

So I have a mild form of narcolepsy that has me awake at night. So for years I thought I had insomnia but it's actually called night wakeness (VA 102).

**PSYCHOLOGICAL FACTORS: COPING STRATEGY****Definition:**

Refers to a cognitive, emotional, and/or behavioral effort directed at managing, reducing, or tolerating the internal and/or external demands of life. The coping effort may or may not be successful and in some cases may have negative effects (e.g. drinking alcohol to manage anxiety). The individual may be more or less aware of using a particular strategy for dealing with a stressor or life circumstance. Coping strategies are not mutually exclusive, although an individual may rely more heavily on a particular style of coping. General or global references to coping or needing to cope that cannot be coded in accordance with the specific categories below should be coded at the parent node. Include when caregiver describes coping strategies employed by Person with SCI, double coded with "Person with SCI"

**Components:**

1. Emotion-Focused: Attempts to cope that are either directly or indirectly focused on managing, manipulating, and/or regulating one's emotional experience in life. Such coping efforts may include strongly cognitive or behavioral elements despite the emphasis on emotional experience. This would include attempts to view an event in a new light such as by "looking for the silver lining" or making comparisons about how "things could be worse." Other examples of emotion-focused coping include: directly expressing feelings to others for purposes of emotion-processing, withdrawing from others to avoid certain feeling states, avoiding talking about feelings, suppressing thinking about a situation or alternatively trying to think it through in order to feel differently about it, engaging in wishful thinking, daydreaming or fantasizing, using sedatives (food, medicine, or alcohol), distracting the self or otherwise achieving emotional distance from a situation such as through intellectual denial or emotional detachment, looking for the humor in life, and the use of calming or relaxation techniques.
2. Problem-Focused: Attempts to solve or somehow resolve a situation, either directly or indirectly, by initiating some type of action or intervention that is aimed at alleviating or remedying the situation. This includes chunking elements of a problem or breaking a problem down into manageable pieces, seeking information, considering alternatives, and direct action. This might also include delaying a decision or action until more information is available or suppressing action to avoid making the problem worse.
3. Social Support-Focused: Attempts to find help in coping with life or a situation by asking for advice, concrete aid, emotional support, affirmation of perceptions, positive regard of actions taken, or other form of social support. The nature of the social support sought may be either formal (e.g., attending a support group) or informal (e.g., talking with friends).
4. Meaning-Focused: Attempts to create or find meaning in one's life experience through reference to a higher being or in reference to the larger scheme of things. This includes the use of an overarching meaning system based on religious, spiritual, or philosophical beliefs and values to change one's image of nature, body, self, society, and culture. Concrete strategies include but are not limited to activities such as engaging in prayer, reading the bible, meditation, and participation in rituals. Some commonly reported

coping strategies include the following: “going to church,” “drawing strength from adversity,” “growing as a person,” “rediscovering what is important,” “feeling transformed,” “taking strength from God,” “finding new faith,” “reading inspirational stories,” “listening to faith-based programs,” an so on.

**Common locations:****Examples:**

Oh yeah, I don’t make a deal out of it; I don’t try to have her embarrassed. In fact I get her out of the situation by rolling her away so no one else knows so she’s not embarrassed by it and we just go do something else.

## **PSYCHOLOGICAL FACTORS: EMOTIONAL STATE**

### **Definition:**

Any description of the individual's emotional state, past or present. Code emotional content regardless whether it is positive, negative, or neutral. Use to describe emotional states rather than psychiatric diagnoses in the cases of depression and anxiety. Include statements caregiver make about person with SCI's emotional state and double code as "Person with SCI"

### **Components:**

1. Depression: Includes any discussion of feeling hopeless, helpless, sad/gloomy/dejected, inability to enjoy life, apathy, emotionally withdrawal, isolated/lonely(regardless of actual social environment).
2. Anger: frustration, resentment, hostility, fury, aggravation.
3. Anxiety: insecurity, vulnerability, concern, nervousness, worry, fear, terror.
4. Surprise/Shock: can range from mild surprise to disgust, horror, repulsion.
5. Stress/Overwhelmed: the emotional aspects of perceived demands exceeding personal capacity. Feeling overcome, overwhelmed, overloaded, crushed by the weight of demands.
6. Grief/Loss: sadness and grief specific to a loss event (may be linked to text that is coded as a Loss Stress Appraisal).
7. Social emotions: emotions in regard to another person or persons – embarrassment, stigma, guilt, love, hate, fondness, connection, companionship, protectiveness (as in taking care of children)
8. Happiness/Joy: positive emotions ranging from contentment/fulfillment/amusement to euphoria.
9. Optimism/Excitement/Hope: future-oriented positive emotions.
10. Gratitude: thankfulness, appreciation
11. Calm: Serenity, peacefulness, relaxed
12. Resilience/Confidence/Self-Efficacy: feelings of strength, adequacy, or of being able to "come back from" "bounce back from" or recover emotionally from difficulty.

### **Common locations:**

Throughout the interview

### **Examples:**

Right. Normally he's pretty patient, but for the most part he gets impatient if I'm not doing things fast enough or doing the exact way that he wants or if I make any kind of a slight change. He's very much schedule oriented. If I do a slight change or don't do it in the order he wants he gets a little impatient with me. And I get a little frustrated with that because for the most part I give 100% at work, to the most of my ability. So when he gets a little impatient it's a little frustrating for me at times, but I always have to keep in mind where he's coming from and try to see it from his point of view .

Considering her condition, she has a very positive outlook on life which she's actually the first quad I've ever worked for that has that outlook cause usually they're very grumpy; they're



stubborn; they're mean and she's not like that by any means. Half the time she's in a better mood than I am (UM 102).

## **PSYCHOLOGICAL FACTORS: STRESS APPRAISAL**

### **Definition:**

The perception that a situation exceeds or may exceed resources and capacity (internal or external) in terms of functioning, adaptation, or coping.

### **Components:**

1. **Challenge**: An appraisal of an event, situation, or life circumstance that may be on the part of the individual. Challenges are more likely to be viewed as “controllable” and may be viewed as having a positive component (“good stress”). Some common challenges are associated with life transitions, such as getting married, childbirth, moving to a new locale, starting school or a new job, etc. Other challenges may be more directly related to the Caregiver work, such as stress involved with certain tasks in the caregiving job- i.e. bladder management. Some challenges may evoke excitement or either positive or negative tone but as requiring unusual or exceptional effort eagerness, while other may evoke some degree of annoyance, anxiety, or self-doubt. Even if a challenge is perceived as exceptional and/or as having potential significant consequence for the individual, it is not viewed by the individual as posing a real or significant threat to physical or emotional well-being. In this sense, a challenge or threat is defined by the individual in that the same stressor might be viewed, alternately, as either a challenge or a threat depending upon personal or contextual factors.
2. **Threat**: Damage that is anticipated and may or may not be inevitable. Threats may be accompanied by strong negative emotions such as anger, fear, and resentment. Some examples of threats are worries about future health and functioning, aging, finances, a loved one experiencing difficulty, etc.
3. **Loss**: Damage that has already occurred, such as the death of a spouse, friend, or pet or an accidental injury that is accompanied by permanent functional losses. Loss could also refer to such situations as loss of a home or damage to a friendship.

### **Common locations:**

Throughout interview.

### **Examples:**

S: So even like now when I commute up to Michigan State 3 days a week. And there's times when if I didn't have to come home and give Maurice [00:43:07] his bowel care program in the morning, I may get a hotel room. I could have gotten a hotel room or my niece actually goes to Michigan State so I actually could have stayed at my niece's and then I have classmates who have all volunteered like, you can stay the night because the weather's too bad to drive home. But I've had to come back to [Ann Arbor 00:43:23] because he needs me in the morning to do his bowel care. And he's nervous because he's on the phone the whole time like, “Where are you now?” So an hour and a half drive from Michigan State turned into a three hour drive.

**QUALITY OF LIFE: QOL REFLECTIONS****Definition:**

Life satisfaction refers to aspects of the caregiver's overall well-being that can be clearly shown to affect and/or be affected by working as a caregiver, by past and current health status (physical, mental, or social), and by life circumstances (household, finances etc.).

**Components:**

1. Expectations: is a label for the broad category of what should be goals, values, standards of comparison, desires, aspirations, wants and needs, etc.
2. Achievements: refers to what the person actually has, is, or controls, such as performances, accomplishments, possessions, relationships, etc. These achievements are held up to the expectations listed above
3. Emotional and/or cognitive response: The individual's assessment of the congruence or gap between his or her expectations and achievements e.g.:
  - a. Happiness or sadness
  - b. Satisfaction/ dissatisfaction
  - c. Zest for life/depression
  - d. positive/negative affect

**Common locations:****Examples:**

As of right now, no. I pay out of pocket cash for everything. But I'm healthy; I don't get sick. I've only gotten sick I think once this year (UM-101).

**QUALITY OF LIFE: SUBJECTIVE QOL RATING****Definition:**

This code refers to the specific question on Quality of Life that appears at the end of the interview and includes a numerical score.

**Components:**

1. Numerical score on QOL (1-10) rating scale
2. Reasons for numerical rating of QOL

**Common locations:**

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**Examples:**

R: And how satisfied you are with the way life is going. On a scale of 1 to 10 with 1 being the absolute worst and 10 being the very best and the middle 5 or 6 being so-so or ok. Where would you say your life is right now?

S: Eight (VA 102).

**SOCIAL FACTORS: SOCIAL ROLE PRIVATE****Definition:**

This code should be used for any talk around a person's role, relationship, or interaction with spouse/partner, children, family, and friends – in general, those with whom the participant has a direct, personal relationship; people that form part of his/her immediate personal-social network. Include caregiver's perspective on relationships between the person with SCI and their family and friends here (double-coded as "Person with SCI")

**Components:**

1. General: perceptions of private life, expectations, roles, relationships, interactions with
2. Roles: spouse/romantic partner, parent, grandparent, family member, friend

**Common locations:****Examples:**

S: We're looking into other plans, but we're hoping we can... My husband's looking at a promotion to a fulltime job here and we'll have benefits. So we're hoping it kicks in before we get penalized on our taxes (UM 101)

S: It makes it difficult sometimes because of course with the children it's not a problem if we travel with our children or very close family members. Like I said we don't travel by car a lot, but it's not really a problem because if he has to cath he will usually cath in the van, we'll just tell the kids or whoever just step out for a second he has to use the bathroom. (VA 102).

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**SOCIAL FACTORS: SOCIAL ROLE PUBLIC SEPARATE CATEGORY FOR RELATIONSHIP  
WITH PERSON WITH SCI/ PERSON WITH SCI FAM AND FRIENDS?****Definition:**

This code should be used for any talk around a person's role, relationship, interaction, or perceptions of life outside of the home including work, community, or volunteering – in general, those with whom the participant has a more formal relationship outside their immediate personal network.

**Components:**

1. Work: relationship with person with SCI's family, friends, and medical care team. Relationships with coworkers. Description of jobs or schooling held outside of caregiver role.
2. Community: Any discussion of community involvement, especially as it pertains to working on outside projects related to SCI
3. Volunteer: Any discussion of volunteering, especially as it pertains to working on outside projects related to SCI, for example fundraising

**Common locations:****Examples:**

S: We do a passive range of motion. Him and his wife... His wife works as a caregiver. She's paid through Accident Fund. And we both do his care in the morning. Because he's a quadriplegic we have to use a Hoyer and it takes two people to use the Hoyer to get him in his wheelchair. So we do passive range of motion on him. We dress him of course, wash him and then we get him up in the Hoyer and get him up in his chair for the morning. Then his wife feeds him breakfast (UM 101).

**SOCIAL FACTORS: SOCIAL SUPPORT****Definition:**

This code should be used for any talk around perceptions and discussions related to support or lack of support provided by others (family, friends, community, person with SCI's family, friends, medical team, other caregivers). Caregivers support staff, such as their supervisor.

**Components:**

1. Friends
2. Family
3. Spouse (may often be double-coded with caregiver)

**Common locations:****Examples:**

Other parents were able to go and truthfully I could go, I could afford to go and I had the freedom to go as far as work or whatever but I couldn't go because I had to care for Maurice [00:34:18] and he didn't necessarily want to go. And I think my family has adjusted pretty well to it like you know when they ask me about things, they'll say what about Maurice [00:34:30]? Who's going to take care of Maurice [00:34:31]? And that says, like I said it feels like having a child. You have to make sure he has the care he needs for me to go do other things (VA 102).

**Focus Group Guide**  
FINAL VERSION  
June 3<sup>rd</sup>, 2015

**Informed Consent Process**

Consents will be mailed ahead of time for review prior to the focus group meeting. Team will bring copies to the meeting to assure final signatures. Consents will be reviewed with participants during the luncheon.

**Time Breakdown**

11:00-11:45	Luncheon; collecting and finalizing consents
11:45-12:00	Break into teams for focus group sessions
12:00-1:30	Discussion of topic questions

**Opening and introductions**

Thank you again for agreeing to participate in our focus group. I'm [name] and I will be one of the facilitators today. My colleagues [names] will also help facilitate. The purpose of this project is to learn about experiences managing bladder and bowel dysfunction and help us understand more about quality of life for those with spinal cord injuries.

First, we are honored that you've chosen to share your stories with us and with each other. These are very real issues and that is why we're conducting this research. However, these are also very personal issues. We want to publicly acknowledge that these questions touch on a very intimate set of personal topics. And we want to assure you that we respect your privacy and confidentiality in this. As such we're asking everyone to use first names only. And to only discuss or address topics when you feel comfortable doing so.

Second, in a focus group it is really important that you express yourself openly. There is no right or wrong answer. We want to know what you think. If you would like to add to an idea, or if you have an idea that is different from someone else's, feel free to jump in. You do not need to wait for me to call on you to talk, but of course only one person should speak at a time. Again, we are pleased that you have taken the time to speak with us today.

Finally, we will audio record this discussion to help record your input for our research; we will erase these tapes after our discussion has been transcribed. We will also be taking notes during our discussion. In any reports of this research, your responses will never be linked with your name.

Because we are recording the focus group, we may remind you to speak up and talk one at a time so that we can hear you clearly when we review the session tapes. Although we are the facilitators, we would like the discussion to flow among you. We only have 90 minutes, so we will keep us moving along.

Let's go around the room and introduce ourselves. Remember to please give your first name **ONLY** and tell us why you decided to participate in the focus group. You don't have to respond in any order; just feel free to jump in.

**Topics and questions for discussion**

Thank you once more for volunteering your time to participate in this project. As we said earlier the project is designed to better understand your experiences with issues of bladder and bowel, how you manage them, help needed, complications, how these impact your quality of life in general, and most importantly at the end we would like for you to share what you learned about your experience with managing your bladder and bowel health so that others can learn too.



We are going to talk about some of the topics brought up throughout our individual interviews, as well as some things we've noticed while reading through everyone's transcripts. Some rules for us to observe while talking: 1) everyone should have a turn to say and add comment as they see relevant; 2) we will need to monitor our time so we can cover all topics so although we do not want you to feel rushed at times we may need to move you right along; 3) it is ok to say what is on our minds as long as we are respecting each other but it is ok to disagree and voice a different opinion or add to what has been said.

**NOTE TO MODERATORS:** Please attempt, in the cases where it seems relevant, to tease out differences between veteran and non-veteran participants in their responses. Also, tease out differences between men and women.

### Section 1 – Bladder and Bowel and QOL Experiences (60 minutes)

1. An important aspect of our interviews with you all has been quality of life how having a SCI or having to live with loss of bladder or bowel function may impact your life. How would you define quality of life? What is QOL for you?

[PROBES AND FOLLOW-UPS – designed to get at conceptualizations of QOL]

- a. What does it mean having a high QOL versus low QOL?
  - b. What important things contribute to or take away from your quality of life?
  - c. When someone asks about your “quality of life” what things comes to mind?
  - d. In what ways do your bladder and bowel impact your quality of life?
  - e. How would you compare your QOL today to before your injury?
  - f. Reiterate: how do you define “quality of life”?
2. We've learned that NBB can greatly impact a person's daily life. What are your top your 2-3 concerns with how NBB impacts your life. Let's talk about bladder first.

[PROBES AND FOLLOW-UPS]

- a. Is it disruptive? Do you have a routine that works for you?
- b. Have you been able to address any these issues? Why/why not?
- c. Are there special things or persons that you found to be especially helpful?
- d. Which of these are most bothersome?
- e. What of these are least bothersome?

How about bowel?

- a. Repeat conversation, but with focus on bowel.

[PROBES]

- b. How do you minimize the impact of bladder and bowel on your daily life?
- c. Can you give us some examples of things have helped you to accomplish this?
- d. How important is bowel and bladder in your list of what you would like to recover if possible? Some say walking is most important, what would you say?

## Section 2 – Caregivers, Healthcare Providers (30 minutes)

3. Some of you have caregivers that assist you with bladder and bowel management. Is that a necessity? Have you had positive experiences?

### [PROBES AND FOLLOW-UPS]

- a. What would you like to change about it to improve it?
  - b. Who is your caregiver? Is he/she paid?
  - c. What things might your caregiver do differently?
  - d. What important lessons have you learned about working with caregivers?
- 
4. Some of you reflected on your experiences with your healthcare providers, doctors and nurses. Do you have any thoughts on your experiences with your healthcare providers that you would like to share? You do not need to disclose any names or identities.

### [PROBES AND FOLLOW-UPS]

- a. What kind of things have healthcare providers done that have helped you?
- b. What can healthcare providers do differently that would help you?
- c. What do you wish they had done for you in the beginning but perhaps did not?

## Section 3: Lessons Learned

5. Experience can be a great teacher, especially when having gone through something like a spinal cord injury. What lessons have you learned in managing your bladder and bowel that we could share with others who are just starting to manage theirs?

### [PROBES AND FOLLOW-UPS]

- a. Where would you like clinical care or research go in this area?
  - b. Are their topics you would like us to focus on in the future?
- 
6. Thinking back on our discussion today, is there anything important that we did not discuss or bring up that you think we need to know?

## **Summary and closing**

We want to thank you again for your time and participation today! This has been very exciting and helpful to us as we move forward in this project. If you have any questions please feel free to contact me. This has been an honor to hear your stories and share this time with you. Thank you!

**DoD Project**  
**CAREGIVERS FOCUS GROUP GUIDE**  
**Version 4**  
**July 24<sup>th</sup>, 2015**

**Informed Consent Process**

Consents have been mailed ahead of time for review prior to the focus group meeting. Team will bring copies to the meeting to assure final signatures. Consents will be reviewed with participants during lunch.

**Time Breakdown**

12:00-12:45	Luncheon; collecting and finalizing consents
12:45-1:00	Wrap up lunch and set up for session
1:00-2:30	Discussion of topic questions

**Opening and introductions**

Thank you again for agreeing to participate in our focus group. I'm [name] and I will be one of the facilitators today. My colleagues [names] will also help facilitate. The purpose of this project is to learn about your experiences assisting someone with bladder and bowel dysfunction and help us understand more about quality of life for those with spinal cord injuries. The relationship between caregiver and care recipient can vary a great deal. The nature of the relationship between the caregiver and care recipient is an important focus of this meeting. It is important to consider the specific (and unique circumstances) that characterize your SCI caregiving as these may vary from caregiver to caregiver.

First, we are honored that you've chosen to share your stories with us and with each other. These are very real issues and that is why we're conducting this research. However, some of your stories may be very personal. We want to publicly acknowledge that these questions touch on a very intimate set of topics. And we want to assure you that we respect your privacy and confidentiality in this. As such we're asking everyone to use first names only. And to only discuss or address topics when you feel comfortable doing so.

Second, in a focus group it is really important that you express yourself openly. There is no right or wrong answer. We want to know what you think. If you would like to add to an idea, or if you have an idea that is different from someone else's, feel free to jump in. You do not need to wait for me to call on you to talk, but of course only one person should speak at a time. Again, we are pleased that you have taken the time to speak with us today.

Finally, we will audio record this discussion to help record your input for our research; we will erase these tapes after our discussion has been transcribed. We will also be taking notes during our discussion. In any reports of this research, your responses will never be linked with your name.

Because we are recording the focus group, we may remind you to speak up and talk one at a time so that we can hear you clearly when we review the session tapes. Although we are the facilitators, we would like the discussion to flow among you. We only have 90 minutes, so we will keep us moving along.

### **Topics and questions for discussion**

Thank you once more for volunteering your time to participate in this group. As we said earlier the project is designed to better understand your caregiving experiences. We are going to talk about some of the topics brought up throughout our individual interviews, as well as some things we've noticed while reading through everyone's transcripts.

Some rules for us to observe while talking: 1) everyone should have a turn to say and add comment as they see relevant; 2) we will need to monitor our time so we can cover all topics so although we do not want you to feel rushed at times we may need to move you right along; 3) it is ok to say what is on our minds as long as we are respecting each other but it is ok to disagree and voice a different opinion or add to what has been said.

Now I'm going to go ahead and turn the tape recorder on. Please feel free to ask any questions along the way and offer anything you think may help us better understand your experiences as caregivers.

**NOTE TO MODERATORS:** Please attempt, in the cases where it seems relevant, to tease out differences between paid and unpaid, family and health agency caregivers.

### Section 1 – Bladder and bowel management (30 minutes)

1. Let's go around the room and introduce ourselves. Remember to please give your first name ONLY. And please tell us a little bit about your care giving experiences and relationship with the person or persons you provide care for. You don't have to respond in any order; just feel free to jump in.
2. Caregiving tasks and relationship and circumstances with those who care is provided can vary a great deal. Everyone may do some things differently or perform unexpected tasks depending on needs and expectations. What kinds of things you do for the person(s) for whom you provide care? What is your relationship to this person?
3. Having to care for someone who needs assistance with his/her bladder or bowel can be difficult at times as it involves issues of privacy, trust, a certain degree of getting used to and moving towards acceptance. This can be particularly difficult when the caregiver is someone who is a spouse, family member or friend, who also interacts with the person with SCI in ways differently from caregiving. These situations may involve social and sexual expectations. Can you tell us about times you've encountered such difficult situations when caring for someone's bowel and bladder?  
[PROBES AND FOLLOW-UPS]
  - a. What aspects of bladder and bowel assistance are most stressful and difficult for you?
  - b. What aspects of bladder and bowel assistance are most difficult for those you care for?
  - c. Explore: probe for family-specific or spouse-specific issues. Sexuality issues.

## Section 2 – Psychosocial aspects of caregiving and being a care recipient (40 minutes)

4. In what ways had your life changed (for better or worse) since becoming a caregiver for someone with a spinal cord injury?  
[PROBES AND FOLLOW-UPS]
  - a. What aspects of caregiving are most stressful and difficult for you?
  - b. From your perspective, what aspects of caregiving are most stressful and difficult for those you care for?
  - c. What kinds of things/what areas of your life are most affected because you are the caregiver for someone with a spinal cord injury?
  - d. Explore: differences between family and non-family caregivers. Paid and unpaid?
5. What role do you play when the person you provide care for is experiencing a lot of stress? How does the emotional distress affect you?  
[PROBES AND FOLLOW-UPS]
  - e. How does it affect you when he/she is experiencing unusual health concerns?
  - f. How does it affect you when he/she is experiencing emotional stress?
6. What do you think of when I say the phrase “quality of life” as it relates to your experiences as a caregiver? For example, how would you rate your quality of life as a caregiver?  
[PROBES AND FOLLOW-UPS]
  - g. When someone asks about your “quality of life” what things comes to mind?
  - h. How would you compare your QOL today to before becoming a caregiver?

## Section 3 – Lessons learned (20 minutes)

7. Experience can be a great teacher, especially when providing care for someone with a spinal cord injury. What lessons have you learned in being a caregiver that we could share with others?  
[PROBES AND FOLLOW-UPS]
  - a. What do you wish healthcare provider better understood about caregiving?
  - b. What do you wish care recipients better understood about being a caregiver?
8. Thinking back on our discussion today, is there anything important that we did not discuss or bring up that you think we need to know?

## **Summary and closing**

We want to thank you again for your time and participation today! This has been very exciting and helpful to us as we move forward in this project. If you have any questions please feel free to contact me. This has been an honor to hear your stories and share this time with you. Thank you!

## Introduction

**This part of the study examined the nature of an intimately interactive relationship—the role daily caregivers perform as they assist individuals who are living with a spinal cord injury (SCI)—as seen through the lens of the caregiver.**

For this, 20 caregivers (either spouses, mothers or agency personnel) verbally shared their experiences of assisting individuals who, in particular, were experiencing SCI bowel and bladder issues. These confidential interviews provided a personal and profound glance at the intricacies, challenges and rewards of the caregiver/care-receiver role. As the caregivers spoke, it became clear that the impact of an educated and supportive caregiving relationship on the emotional and physical health of those with SCI was a critical priority—especially when it came to learning about and managing bowel and bladder needs. Caregivers described their relationship with those they aided as close, two-way, and even symbiotic.

According to the literature, health behaviors and environmental supports, including relationships with family and caregivers, are imperative to consider when examining modifiable factors that may influence bladder and bowel complications after SCI. Personal forces affecting behavior related to complications include depression, anxiety and fear of incontinence, which can significantly limit one's ability to engage in intimate relationships and social activities outside the home.<sup>10</sup> Related concerns include increased stress and withdrawal, dependence, and difficulties with sexuality.<sup>10,25</sup>

The implementation of bladder and/or bowel programs pose additional challenges to those with SCI as this often requires assistance from family, friends and paid caregivers, use of special equipment, medications and environmental adaptations to improve accessibility. These programs can be time consuming and difficult to perform, some requiring exposure to unpleasant and embarrassing events, thus generating further stress within already overtaxed relationships and/or role reversals among partners, caregivers or other family members.<sup>26</sup>

Clinical experience suggests that the availability of and quality of caregivers is a critical factor in predicting the ability to maintain health and prevent complications. Spouses who provide care for persons with SCI report feeling significantly more physical and emotional stress, burnout, fatigue, anger and resentment than non-caregiving spouses do.<sup>27,28</sup> Sexuality and intimacy are often affected by these problems.<sup>29</sup>

The experience of increased stress by family members, caregivers and persons with SCI may in turn make it more difficult to follow treatments to prevent complications. Stress can interfere with health behaviors critical to successful bladder and bowel care, such as following a proper diet and adhering to prescribed treatments.<sup>7</sup> Anecdotal accounts of soldiers returning from current wars suggest a direct link between loss of bladder and bowel functions and loss of manhood among these service men. These perceptions are likely to shape their behaviors, affecting their health and well-being as well as their ability to survive with SCI.

Focused on caregivers, this qualitative component of the overall study provided an in-depth look at the role of providing bowel and bladder care in preventing complications and enhancing quality of life (QOL) in persons with SCI. In order to identify risk factors associated specifically with neurogenic bladder and bowel complications after SCI, investigators concentrated on four major content areas as perceived by SCI caregivers:

1. The most *stressful* aspects of caregiving
2. How caregiver involvement in delivering bowel and bladder care *differs* depending on whether caregivers are family members
3. The differences, if any, that exist between caregiving for *veterans and non-veterans*
4. *Other major caregiving issues* as they relate to those they provide care for

## Methods

To complete the goals of this portion of the study, investigators used a qualitative social research methodology, conducting *individual interviews* and *one focus group* session with SCI caregivers.

### Sampling and Recruitment

Purposive sampling was used to select 20 caregivers as study participants. This ensured a balanced representation of those who were caring for individuals with respect to time since injury (TSI), neurological level of injury, gender and other SCI participants' characteristics. TSI was used as the main criteria for sampling due to its potential effects on bladder and bowel issues. Second, investigators included comparison samples of caregivers who were attending to either civilians or veterans with SCI. Attempts were made to get a mixture of family, and non-family paid caregivers.

Caregivers were recruited from UMHS based on selected SCI participants from the U-M SCIMS database and the associated SCI Research Registry (over 900 persons with SCI). Veterans' caregivers were recruited from Dr. Diponio's VAAHS clinics (over 180 persons with SCI). Additional recruitment occurred through MPVA, as needed to provide diverse representation. Focus group participants were then recruited from these selected samples. Participants were invited to join the focus group based on a review of their transcripts and first impressions of interviewers about their ability to articulate critical opinions and impressions related to the study topic.

Eligible caregivers were required to have worked with those who had traumatic and non-traumatic SCI for at least 30 days, were ages 18 to 70 and were able to understand questions and verbally communicate in English without problems. A brief phone screening was completed by the Program Coordinator to ensure adequate eligibility, arrange for informed consents, and interview scheduling.

<b>SCI Caregivers of SCI Participants/Years Post Injury</b>	<b>UMHS</b>	<b>VAAHS</b>
Of those recently injured	5	0
Years post injury: 10-or more	5	10
<b>Totals (N=20)</b>	10	10

### Data Collection

During the first two years of the project, in-depth semi-structured individual interviews were conducted with the 20-person caregiver sample. Interviews took place in person whenever possible, usually at the clinic locations. Telephone interviews were held when these arrangements could not be made and other venues could not be arranged. Interviews lasted between 1 and 2 hours. The core of each private interview consisted of a series of questions designed to address the research topics posed above. To enrich and deepen the data content, the one six-member caregiver focus group was convened and conducted during the third year. This two-hour focus group session was held in a conference room in the Burlington Building, a center for UMHS outpatient services. It began with a light lunch, which facilitated informal introductions and casual conversation.

In both sets of individual and focus group interviews, caregivers were asked questions in relation to their personal, professional and social needs. Researchers requested that they



identify especially stressful aspects of care provided, as well as resources needed. For spouses and partners who served as caregivers, identifying difficult issues in discerning their sexual versus caregiving roles were probed as well. Highly trained and experienced individuals, one of whom has a physical disability, conducted the interviews. All interviews, whether individual or group, were audiotaped and transcribed for later analyses.

### Data Analysis

The resultant categorizing of information drawn from caregivers is both quantitative (demographics) and qualitative (themes and patterns). A major goal of qualitative analysis is identification of topics, themes, and patterns in the data and the drawing of inferences about their meaning. “Topic” refers to a substantive focus of a participant’s remarks, e.g. bladder or bowel complications, such as UTIs. “Theme” refers to narrative data reflecting the thoughts, feelings, impressions or perspective of a study participant. “Pattern” refers to inferences the researcher makes about narrative material for analytic purposes. For this study’s qualitative data analysis, themes and patterns of caregiver responses are reported here in direct response to the four major content areas.

## **Results**

### Quantitative Findings: Demographics

Family caregivers assisted 60% of the veterans with SCI; 40% had non-family caregivers. Fifty percent of the non-veterans with SCI were assisted by a family caregiver; 50% had non-family caregivers.

Caregivers’ average age was 45 years, ranging from 21 to 69. Eighty-five percent of the caregivers were female. Sixty-five percent of caregivers assisted someone with tetraplegia from SCI; 35% assisted an individual with paraplegia. Every caregiver interviewed had aided with bowel and bladder management. Eleven were family members, nine were agency personnel. Sixty percent of this caregiver group was married and of those who were married, 50% had been married to or living as a significant other with their SCI care-receiver. Thirteen caregivers assisted only one individual, while seven provided services to more than one person with SCI.

Thirty percent (n=six) of this caregiver sample took part in the subsequent two-hour focus group. Two of the six had assisted a veteran with bowel and bladder management. The

remaining four had assisted non-veterans experiencing bowel and bladder issues. All but one of these participants were or had been married to their care-receiver. Half of this group assisted those with tetraplegia, the other 50% helped individuals with paraplegia.

### Qualitative Findings: Themes That Emerged From Individual Interviews

#### ***The Most Stressful Aspects of Caregiving***

*Veterans' Family:* Two thirds of the veterans' spouses described their stress as coming from the pressure of being the primary and only caregiver—that their spouse was overly dependent upon them. They expressed that if the topic of bringing in extra help was brought up, the one they cared for often did not want another caregiver—especially due to privacy issues around bowel and bladder care. Another reason was that having aides seemed a difficult proposition. Aids were difficult to find, not well trained, not dependable, and seemed like invaders in the household—more hassle than going it alone. One woman did not even trust VA hospital nurses to care properly for her husband with a pressure sore. On one occasion, as they were entering the hospital with a pressure sore to be treated she remarked,

“I had to be really strong. I (said to the nurses), ‘You know what I’m going to do? Take a picture now and then take a picture before he goes home. And I will sue you if it’s bigger!’ I have to be mean...like a superman.”

These family caregivers often felt the stressful burden of being trapped, even though they loved their spouse. Several mentioned that providing bowel and bladder care for a person with SCI was like having a child at home who required constant, often round-the-clock, very structured attention and supervision. During the course of the interview, one veteran’s wife asked, “Why hasn’t there ever been a movement to fight for the rights of caregivers?”

More than 50% of these family caregivers of veterans also spoke about how stressful traveling with their spouse had become. Inaccessible bathrooms on airplanes and in hotels prohibited proper bowel and bladder care. Often the person with SCI was afraid to travel due to the possibility of having embarrassing elimination accidents (especially bladder) with no recourse for cleanup. This left caregiver spouses feeling stressed because they did not want to travel without their husbands, but also needed to travel for business or social reasons. Many caregivers felt they could not leave, which led to a situation with no respite for them, creating

greater stress. Those who did travel encountered barriers that made it difficult, as described by one wife...

“Oh we went to Cancun one year and we were told by the travel agency that there would be kneeling busses and everything would be accessible and there would be no problem. And we got down there and they had to carry him off the plane because they didn’t have the jet way...you had to go down the stairs. There was no kneeling bus or not even a cab that he could get into to get to the hotel. So everything they told us was wrong. Their cabs down there are all little sub-compacts, so they couldn’t even get his wheelchair—because we took the electric chair—and they weren’t able to get his chair into the cab so once we got somewhere, we couldn’t get out. We found some cab driver’s brother who had an old LTD...with a big trunk... four or five little kids down there, teenagers would lift the chair up into the trunk...then...when we got there...a bunch of kids would come running out and we’d give them each a dollar. They would unload the chair. We made it work, but it was stressful.”

*Veterans’ Non-Family:* Among these four caregivers, two major stressors were mentioned most often: empathetic distress and low wages. Among non-family caregivers how the care-receiver was feeling and how they treated them could be a source of stress if it was negative. One caregiver shared:

“...he could really...take his bad mood out on me, he might be swearing and ...yelling at me and I have to understand that it’s nothing I did, just the mood he’s in...it’s not my fault but I’m going to let him take it out on me because who else does he have to take it out on?”

Another reveals:

“His wife will come in and argue with him and that stresses me out...sometimes he gets just sad...his daughter passed away a while ago in a car accident...he had a nephew who passed away six months ago with a disability. If I see him tear up I get...sad for him.”

The need to raise agency caregivers’ hourly rates to a living wage was also mentioned more than once. Low pay could create a need to work long hours and that combination could become distressing and over time, health-depleting. Other sources of stress for this group included fear of failure as they initially learned to help clients manage bowel and bladder regimens. These could involve adapting to the person’s privacy needs, medical equipment use and daily scheduling of bowel and bladder procedures.

*Civilians' Family:* There were three major sources of stress expressed by these caregivers who were family members. First, there were the incessant daily demands and worry associated with caregiving, especially related to bowel and bladder care, and once again, feeling overly needed. One wife confided,

“...it literally drives our life. His bowel. Between his bladder and bowel routines, in timing, our whole day, our whole life is scheduled and driven around it.”

There was constant solitary pressure on the caregiver to stay hyper-vigilant and to be exceptionally well organized. One widow recalled,

“I was getting the brunt of everything. When there was frustration, it was out on me. When he was ill, I took it on or I fixed it or I tried to make it better. It was always me. It was stressful...I did everything...laundry, yardwork, house, cleaning...It just consumes you.”

The second major stressor was the development of new caregiver health issues brought on by the caregiving role's requirements. These burdens created new personal distress, uneasiness and responsibility for time-consuming self-care tasks. One wife developed a chronic allergic rash syndrome, others began to overeat, gain weight and become subject to new health threats due to obesity. One husband shared,

“All I want in life right now...is to be able to take care of her. That means both physically and mentally to be there for her. That's my number one focus. Now my own well-being is kind of taking a back seat to that but I don't see any other option.”

The third stressor was the confusion over the role of caregiver versus the role of spouse. As one woman said,

“The role of caregiver versus lover versus partner really was meshed and I think it was very, very difficult for both of us...I was in that caregiving role all the time and it was just really hard to shift gears.”

*Civilians' Non-Family:* For this group of caregivers, negative interactions with clients was also most often mentioned as a stressor. Because the relationship with a client who has bowel and bladder issues in particular is quite intimate and repeatedly routine, caregivers are often exposed to the feelings and responses from their clients. One caregiver spoke of clients with SCI that were distressing to work with,

“I dealt with four or five different ones. They are usually mean, rotten, nasty people. I had some spit food out on me and tell me insulting, horrible things because they’re so unhappy with their way of life...how they ended up.”

Another caregiver revealed stress related to her empathy for the client,

“So if you see that person going through any emotional, physical or anything health wise, you’re concerned...that emotion...would go to me too. I would feel that emotion of worry and I would stay... stressed about that person is going through and wanting to make things okay...because as a caregiver, I want to fix everything.”

These agency caregivers were also often stressed about having very long hours, no medical benefits and low wages. The third major stressor for this group was trying to get enough sleep (or trying to operate in a sleep-deprived state), staying healthy and physically fit, with no injury. The nature of their job is physically demanding and good health is a priority requirement for them to maintain their employment status.

***Differences in delivering bowel and bladder care depending on whether caregivers are family or non-family members***

All family caregivers administered both bowel and bladder care to their care-recipients. Of the 11 family caregivers, nearly 50% had been health care professionals before they met and married their care-receiver. Three of the 11 were their mate’s sole caregivers. Eight family caregivers had the help of paid aides throughout the day and took on managerial roles, overseeing employees’ duties. The three sole family caregivers assisted with bowel and bladder routines more often than others did.

Several of these family caregivers revealed that this time spent together during bowel and bladder care actually strengthened their marital relationship, rendering their communications more profound and fulfilling than before the injury occurred. One wife shared that it was a time of closeness for just the two of them that they both looked forward to every day. Of their relationship, one husband further told us that he valued his wife more than ever because he almost lost her. Another husband said, “...we want to do so much together still...her injury hasn’t detracted from that at all”.

Because they were in long-term marriages/relationships, family caregivers had a better sense of the big picture about the progression of bowel and bladder problems. They were able to

share a complete timeline of medical events. They possessed a sense of continuity and longevity of care over the decades that paid caregivers could/did not report. Several wives were able to tell the long-term stories explaining in detail the progression of their husbands' bowel and bladder issues and the resultant medical complications that eventually led to their spouses' deaths. In addition, their perspectives were more all-inclusive when it came to the support and home life of their care-receiver because there were more elements to consider, including their own role as a family member. Example questions they needed to answer included: what role would kids play in this care? How many aids were needed and how were they to be trained? How does one balance and separate being a spouse/lover verses being a caregiver? Who will do the household chores, as opposed to bowel and bladder care and when? How does one set personal boundaries around caregiving in your own home and plan respite time?

While family caregivers shared a more all-embracing family dynamics perspective, paid caregivers demonstrated a more constricted view when it came to describing their daily work in delivering bowel and bladder care. For example, wives/husbands lamented about how bowel and bladder issues could abruptly halt a social event or prevent a family plane or car trip limiting social connections; non-family caregivers expressed great concern about learning the detailed techniques of proper bowel and bladder procedures. Of the nine non-family caregivers, six worked part time; three worked full time. They could go home after their work; family caregivers *were* home. Both had difficulty adjusting to bowel care in particular. It was smelly. After adapting to the specific care techniques however, both described the bowel and bladder procedures as having become easy and routine.

In addition, non-family caregivers expressed very strong sensitivity and repulsion to negative feedback, and abusive behavior from their clients. They complained more intensely than family caregivers did when their care receiver was mean and disapproved of their work. One woman shared,

“I have a client (who) was mean as a snake. And she was paralyzed from the waist down but her hands didn't work real well either so she had to be cathed every two hours. So I would straight cath her every two hours and she would make (me) do it in the dark with no light. All you had was...an itty bitty flashlight that didn't hardly give you any light

and you had to do it without waking her up and then trying not to miss on top of that. And then when you woke her up, she would just scream at you...call you stupid.”

In contrast, they grew a deep and abiding compassion and empathy for care-receivers who were positive and appreciative. Bowel and bladder care time often became a cherished one-on-one time with a beloved person who simply needed help with SCI issues.

### ***The differences that exist between caregiving for veterans and non-veterans***

Three of the 20 caregivers did describe the personal qualities they witnessed in the veterans they assisted. The first described her care-receiver as very focused, “like a Marine...”

“If he was going to do a job, it was going to get done right and it was going to get done quickly. He...didn’t feel sorry for himself: ‘if this is the way it’s going to be, this is the way it’s going to be. Let’s move on...and we’re not going to sit and cry about it.’”

The second caregiver referred to self-confidence and having a support network among fellow Veterans...

“He knew how to fly a plane for four years, so he’s been doing this for 30 years too. I think he has confidence in what he knows and what he can do. He has a good network of friends too (as a Vet).”

The third described Veterans’ aversion to seek counseling...

“Trying to walk alongside them as they redefine who they are or refuse to in some cases...and so many veterans won’t use the help they get, as far a psychological help...there’s a military stigma against mental health (counseling).”

### ***Other major caregiving issues***

Additional issues that were cited less frequently by veterans’ family and non-family paid caregivers included dealing with medical equipment failures, tedious bureaucratic difficulties getting medical supplies through the Veteran’s Association, struggling with repeated UTIs, and economic issues. Because the family caregivers were unexpectedly “forced” into a new life role, it was burdensome to rapidly learn how to be a good caregiver immediately following the onset of injury. For family caregivers of civilians, problems also mentioned included adapting to mood swings in the care-receiver, dealing with inaccessible bathrooms in the community when there were bowel and bladder issues that arose (which often resulted

in rushing home), and the initial anxieties and pressures of learning the role of caregiving during the acute phase of the spinal cord injury. Non-family caregivers of civilians cited other stressors, including the continual demand for exacting care for clients with bowel and bladder needs, such as maintaining sanitation procedures; and having to be extremely thorough with care all the time.

### Topics, Themes and Patterns That Emerged From the Focus Group Discussion

Information gleaned from this focus group supported findings from the interviews above, providing more detail and elaboration on major topic areas that were discussed. During the session, two categories of caregiver issues emerged as dominant:

#### ***Stress***

The prevalent theme was that this group's major source of stress is that they must be constantly vigilant as caregivers, around the clock. Caregivers expressed a need for more respite time away from their care-receiver. They offered suggestions for structured time off activities.

#### ***Quality of Life/Relationships***

Most focus group participants were spouses of the person with SCI. They defined high quality of life as being able to actively participate in the community. Inadequate bowel and bladder regimes had interrupted this activity for spouses on occasion, and had become burdensome. Effective management tactics took trial and error approaches along with enduring patience to master. They also referred to adapting to their changing spousal roles after SCI. They said that they and their care-receiver had become closer as people, but several did not sleep together anymore. Additionally, caregivers said that they struggled with feelings of social isolation and lack of external support.

A closer review of the Caregivers' Focus Group transcript elucidates these major themes in greater detail:

- It is hard work that often involves 24/7 vigilance  
*Spouse: "I'm always constantly thinking about her".*  
*Non-Spouse: "...the stress is feeling responsible for the person...one wrong move..."*  
There is also worry about what will happen to spouse in the future.



- Having to learn new skills to do new tasks that they never thought they'd have to do  
*Spouse: "I am surprised at how adept I have become at fixing things...I don't want to, but yes."*
- Money, medical insurance issues  
Dealing with the financial, medical, insurance and having to pay out of own pocket is stressful. Those who had good insurance expressed their gratitude. Obamacare helped one family.
- Bowel routines must be tested and highly scheduled. They take time. Discomfort can occur if the routine is postponed for social reasons. In addition, accidents can suddenly interrupt the day's activities and must be attended to spontaneously.  
*Spouse: "the whole process of getting ready in the morning (including dressing, bowel and bladder management) is time consuming."*
- Bladder routines  
Comments included that independent cathing provides more freedom for activity during the day, otherwise there is a strict schedule needed for the person with SCI and his caregiver, which impedes activity, especially any distance traveling.  
*Spouse: "(Cathing) is the number one deterrent in the way we live our lives."*
- Regimentation Training  
Caregivers commented that being trained in the military/police force to be regimented helps the person with SCI in adapting to the needed lifestyle changes including bowel and bladder management programs after SCI.
- Sleep issues  
*Spouse: "I sleep in another room."*  
*Spouse: "We don't sleep together."*

### **Associated Feelings, Perceptions that Caregivers Experience**

- Grief  
One wife caregiver was grieving the death of her husband; another was grieving the loss of life's activities before his wife's SCI.
- Isolation  
Caregivers expressed a sense of isolation and a need for a network of friends who understand.  
*Spouse: "When you're stuck in your house and in this little world...and you want to go do something and you can't..."*  
*Spouse: "...to be more open with my friends that there are problems...that ...this is hard..."*
- Expressed Needs  
Better rehabilitation education from hospitals, social workers are needed to teach about care techniques

- **Respite Time**

*Spouse: "I lose a little bit of time for myself...needing to get away, but can't get away..."*

*Spouse: "I can't go home (like paid caregivers). I'm home, you know and how do I not...take my frustration back out on...?"*

*Spouse "I have a group of friends...we go for three days every year up north...that's my vacation...those three days".*

*Spouse: "my going upstairs was ...my break."*

More structured respite time was a strongly suggested solution to these caregiver issues of stress and isolation. Group members suggested they would like to go to caregiver meet-ups at Starbucks or to an organized caregiver camping retreat for a weekend.

- **Quality of Life/Relationships**

A high quality of life was associated with the ability to actively participate in the community with one's spouse who has SCI.

*Spouse: "...quality of life...to be active still."*

Effect of Caregiving on Relationship with Care-receiver

Strong sense of closeness; there is a bond, connection that caregivers develop with those they are caring for.

*Spouse: "So it brought us closer together, yes, but 24/7 with a spouse isn't the most ideal thing..."*

*"Others said, 'we can see how unified a unit you are now, and you didn't seem that way before.'"*

Dual roles as spouse; sexuality combined with caregiver role gets blurry and confusing

*Spouse: (When helping with bowel and bladder function) "...a spouse just doesn't do this...you're intimate. You know your spouse's body, but you shouldn't know it this well..."*

*Spouse: "(since her injury) I slept upstairs...she slept downstairs...you lose a lot of that intimacy..."*

*Spouse: "We were lucky we had each other...he was my mental caregiver; I was his physical caregiver..."*

During the course of the caregiver focus group, it did not become clear how involvement in delivering bladder and bowel treatments differs depending upon whether caregivers are family members. This was not discussed in detail. It was clear that caregiver spouses were under pressure to perform around the clock, whereas paid caregivers could separate and go

home. It was also clear that dealing with bowel and bladder issues could affect quality of life for persons with SCI and their caregiving spouses. Well-organized management regimes are learned over time and crucial to maintaining the highest quality

## Summary and Conclusion

This report describes information gleaned from 20 caregivers of individuals experiencing bowel and bladder issues after a spinal cord injury. The accounts from family and non-family caregivers of veterans and civilians were examined in the context of four content areas:

1. The most *stressful* aspects of caregiving
2. How caregiver involvement in delivering bowel and bladder care *differs* depending on whether caregivers are family members
3. The differences, if any, that exist between caregiving for *veterans and non-veterans*
4. *Other major caregiving issues* as they relate to those they provide care for

In reviewing the testimonies of these care providers, several key patterns emerged.

In caring for veterans, the most stressful aspect of caregiving shared by family members was **the pressure of being the primary caregiver** in charge of everything, with little time for respite. This was repeatedly expressed in private interviews and substantiated again in the focus group session. For non-family caregivers of veterans, **feeling unappreciated, not respected and even emotionally abused** was an intense source of distress, when it happened. In caring for civilians, once again family members' major stressor was the pressure of being the primary caregiver, and feeling consumed by the role. For non-family members, negative feedback and interactions with clients was terribly distressing.

In reviewing the major difference between family verses non-family member involvement in bowel and bladder care, this can be summarized as *the individual's perspective* on that care. Both groups said that bowel and bladder care became perfunctory and routine after the initial learning phase. Family caregivers, however, expressed a much more **all-embracing perspective on this care** in two ways: they could interpret and describe bowel and bladder care as it played into the bigger picture of family life and became care managers as well as caregivers. They could also describe the changing nature and complications associated with

caring for their care-receiver over the lifespan. Non-family members expressed a **simpler perspective** as they gave bowel and bladder care: be conscientious and compassionate, do a good job in the allotted time, then go home.

Limited information garnered from this study's subjects provided only a **preliminary glimpse** at possible differences between providing care to veterans verses civilians. It may be that veterans adapt to the routine care required for bowel and bladder management because of their self-confidence resulting from military work, ability to focus on a task, familiarity with military discipline and regimentation and the support of their associated network of veterans. More studies need to be conducted in order to investigate and adequately answer this particular question.

Finally, the other major issues around bowel and bladder care for veterans included struggles with recurrent **urinary tract infections and procuring and maintaining medical equipment** from the Veterans' Administration. Additional issues for civilian care had to do with **inaccessible bathrooms** in the community needed in order to administer care outside the home. Family caregivers of both veterans and civilians expressed how stressful it had been to **learn the role of caregiver** immediately following their care-receiver's SCI onset.

In conclusion, the results of this study of bowel and bladder caregiving creates an opportunity to develop new questions and engage in a more informed discussion about the issues and answers these caregivers have now left in the hands of researchers. How can family caregivers find greater balance as they manage life with a dependent spouse (or child)? What and who would help with this? How can non-family caregivers learn to best handle abusive clients and fight for higher wages, medical benefits and shorter hours? Who will advocate for them? Finally, if their daily caregivers received help with unaddressed stressors and issues, would individuals with SCI who require bowel and bladder care receive better care, stay healthier and live longer as a result?

## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group One

May 14, 2016

Sunny Roller, M.A.

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After studying the SCI Participant Focus Group One transcript, three dominant themes emerged:

- 1) A grievous loss of daily spontaneity during the months immediately post-injury gave way to the realization that this former freedom must be replaced with a fastidiously planned daily schedule for bowel and bladder management. Keys to success in this area include:
  - a. Individualized methods of bowel and bladder elimination processes
  - b. Proper dietary intake, health habits
  - c. Effective communication with caregivers
- 2) A major impediment to proper healthcare for this group is the lack of physicians in the community who are knowledgeable about the medical needs of patients who have a spinal cord injury.
- 3) A person's perception of a having a high quality of life is individual. It also is dynamic; goes up and down on a daily basis. High quality of life includes participating in a full range of experiences. It is important to be diligent about managing bodily functions and to stay positive.

*Participants addressed risk factors for complications by describing how they try to prevent problems and spoke generally about attitudes and health management behaviors that can lead to a high quality of life.*

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A closer review of the SCI Participants' Focus Group One transcript elucidates these major themes in greater detail:

### **1) Pre-Injury spontaneity is replaced with a planned daily bowel and bladder program**

- A person's bowel and bladder care "definitely affects spontaneity. You got to plan a lot more."
  - "Even if you do plan it, you don't know what the hell is going to happen."
  - ***"The bladder and bowels are the biggest challenge. I mean for me...I'd rather not ever have a possibility of walking again as long as I had the possibility of my bladder and bowels back again."***
- a) Individual management strategies and tactics

## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group One

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- "It takes one to two hours in the morning. "And then there's this whole Zen, mind-fuck thing to it that if you try to hurry up, it's going to take longer." Or you're going to stop before you're done and then you're going to have an accident somewhere."
- "If I have a bad bowel movement...then my bladder is messed up the whole day...and I can't trust it so I might as well pack it up and stay home."
- "I follow a cathing schedule if I drink a lot of water." "I try not to wait for the feeling..."
- "...carrying my urinal around everywhere...I self-cath and they don't make catheters long enough that you can pull up to a toilet..."
- I always just have a bottle and when I go into the bathroom, I'll just self-cath into the bottle, dump it into the toilet and that way I don't carry it around."
- A suprapubic tube: "It goes through the abdomen into the bladder. (Urine) flows constantly...into the bag and then you just drain the bag."
- "I don't want no surgeries..." "I hate having surgery for something; they screwed me up worse than before I went in."

### b) Dietary Intake, health habits

- "...if I don't eat well and I'm constipated and I have problems with my bowels, then that's when my bladder is irritated".
- "You got to make sure to eat your fruits and your vegetables. I take a probiotic—helps these to come out a lot quicker."
- "I just make sure I eat a lot of fiber to get that movement every day."
- "Keep hydrated but if I drink too much then my bladder will have issues and if I don't drink enough then I have bowel issues."

## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group One

May 14, 2016

Sunny Roller, M.A.

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- “I’m better off eating little bits...” “...constantly sip...” It helps prevent bowel/bladder accidents.
  - “I quit smoking like five years ago and like UTI infections have cut in half.”
  - Alcohol and sugar cause bladder infections
  - Keep hands clean to avoid infections. “It would be helpful if they would keep...hand sanitizer...inside handicap (bathroom) stalls...”
  - Cranberry pills help ward off infections.
- c) Effective Communication with Caregivers
- “You got to be open and honest.” “...you got to be able to let them know the worst details...”
  - “I think more attention (needs to be paid) to the caregiver and giving them more information.”

### **2) Lack of knowledgeable physicians, healthcare professionals is an impediment to good health**

- At the hospital, “a lot of people there don’t know...about the spinal cord, bowel care, bladder care; they know none of that stuff.”
- “I had to go to Urgent Care and they didn’t know how to take the urine.”
- At the VA, “there’s been times where I’ve had to wait a long time for an appointment”.
- Lack of access to exam tables in doctors’ offices...”the tables aren’t set up for us to get up...”
- “You have to be your own advocate.”

## **DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group One**

May 14, 2016

Sunny Roller, M.A.

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### **3) Quality of life with bowel and/or bladder issues is based on individual perceptions and perspectives**

- “Keep a positive attitude.”
- “Don’t get discouraged.”
- On bowel and bladder regimen: “You just have to deal with it.”
- Don’t “let a bowel/bladder accident kind of completely ruin your self-esteem...because they are going to happen, but you always live through them...the next day always comes...”
- “Stuff going to happen and it’s not going to end your world.”
- Communicate clearly with bosses.
- “Don’t give up and listen to your body.”
- “Having a job does a lot for you.”
- Perspective changes. “You get better.” “I find other things to get into.” “It’s getting a good, full range of experiences in this life...”
- “Everything happens for a reason.”
- “Quality of life changes from day to day.” “...everybody’s expectations are different I guess.”
- “Your life is what you make it, whether you have a spinal cord injury or not.”



## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group Two

May 15, 2016

Sunny Roller, M.A.

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After studying the SCI Participant Focus Group Two transcript, two dominant themes emerged:

1. To maintain a high quality of life characterized by independence, knowledgeable daily diligence to manage personal bowel and bladder function is crucial. There are numerous successful methods employed by this group.
2. Effective bowel and bladder management involves a “balancing act” that changes over time, affects personal/intimate relationships and participation in the community.

*Participants addressed risk factors for complications by describing current practices that are mostly successful for avoiding complications.*

*Complications that affect quality of life the most had to do with intimate personal relationships and the ability to travel.*

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A closer review of the SCI Participants’ Focus Group Two transcript elucidates these major themes in greater detail:

### **1) Diligence**

a. “The biggest thing for me was getting down to the schedule and...” “maintaining it.” It’s a lot of work.

b. Quality of Life was defined as “being able to do things on your own”. But it was

dependent upon bowel and bladder management. “...That’s always an issue as far as getting out and being independent, and being able to know your body...” and how to manage bowel and bladder functions

c. Bowel Issues

## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group Two

May 15, 2016

Sunny Roller, M.A.

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- i. Bowel issues create travel limitations. "...they go hunting out west and those are trips I can't do anymore...not being able to take care of myself."
    - ii. Large bowel movements, constipation are a concern
  - d. Bladder issues
    - i. "The bladder function...really draws me down." Cathing "was one of my biggest things I had to accomplish..." before going to work.
    - ii. "I end(ed) up having...bladder augmentation surgery."
    - iii. There are catheter kits, and "the clean method", catheters that have tips on them for ease of use, mechanisms to pull underwear down, and condom catheters.
    - iv. They described accidents and complications. "I've had to pee in the back of my mail truck...because I couldn't hold it." "Over the last two and a half years I've been in the hospital with...a urinary tract infection or a bladder infection.
- 2) **"Balancing Act"** "It's like my whole life has been a balancing act." "As I get older...things are getting worse." More complications. If attend to one issue, must watch out for another problem that could occur because of it.
  - a. Negative emotions
    - i. Anger about life difficulties, self-flagellation about getting the SCI
    - ii. Fear. Worry about the future: "it's scary for me..." "...you worry...every time you lose something..." (physical ability)
  - b. Management strategies
    - i. It is valuable to know body signals and predictors for urinating: headache, tingle on shoulders, and bottom of shirt wet, heat and cold stimuli.

## DOD Project: Summary of Salient Issues from the SCI Study Participant Focus Group Two

May 15, 2016

Sunny Roller, M.A.

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- ii. Set a schedule: "I have a digital watch and I'd set my alarm to the next time I'd have to cath."
- iii. Dealing with what supplies insurance companies provide is challenging. They are often not up to date on their product information.
- iv. Military guys are "a little bit more gung-ho to go forward...ready to accomplish..." They demonstrate "mental toughness".
- c. Personal relationships
  - i. Loneliness. Bowel and bladder issues have a "huge impact...girlfriends, dating...sexuality". "Having your leak when you're in bed with your girlfriend, you know, it's like devastating, at least if it's the first time..." "I don't even look at women anymore." (Shame connected to projected bowel issues.)
  - ii. "As far as women...you shouldn't worry..." "Them women love helping us...they start out relationships, then become caregivers..."
  - iii. ""My wife is really hurting from taking care of me."
  - iv. Having a dog encourages socialization.
  - v. "Reach out and smile."

## DOD Project: Summary of Salient Issues from the Caregiver Focus Group

April 13, 2016

Sunny Roller, M.A.

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After studying the Caregiver Focus Group transcript, two categories of caregiver issues emerged as dominant:

- **Stress**  
The prevalent theme was that this group's major source of stress is that they must be **constantly vigilant as caregivers, around the clock**. Caregivers expressed a need for **more respite time** away from their care receiver. They offered suggestions for structured time off activities.
- **Quality of Life/Relationships**  
Most focus group participants were spouses of the person with SCI. They defined high quality of life as being able to actively participate in the community. **Inadequate bowel and bladder regimes had interrupted this activity for spouses on occasion, and had become burdensome**. Effective management tactics took trial and error approaches along with enduring patience to master. They also referred to **adapting to their changing spousal roles** after SCI. They said that they and their care receiver had become closer as people, but several did not sleep together anymore. Additionally, caregivers said that they struggled with feelings of social isolation and lack of external support.

A closer review of the Caregivers' Focus Group transcript elucidates these major themes in greater detail:

### 1. Stressful Aspects of Caregiving

- a. It is hard work that often involves 24/7 vigilance  
*Spouse: "I'm always constantly thinking about her".*  
*Non-Spouse: "...the stress is feeling responsible for the person...one wrong move..."*  
There is also worry about what will happen to spouse in the future.
- b. Having to learn new skills to do new tasks that they never thought they'd have to do  
*Spouse: "I am surprised at how adept I have become at fixing things...I don't want to, but yes."*
- c. Money, medical insurance issues

## DOD Project: Summary of Salient Issues from the Caregiver Focus Group

April 13, 2016

Sunny Roller, M.A.

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Dealing with the financial, medical, insurance and having to pay out of own pocket is stressful. Those who had good insurance expressed their gratitude. Obamacare helped one family.

- d. Bowel routines must be tested and highly scheduled. They take time. Discomfort can occur if the routine is postponed for social reasons. Also accidents can suddenly interrupt the day's activities and must be attended to spontaneously.

*Spouse: "the whole process of getting ready in the morning (including dressing, bowel and bladder management) is time consuming."*

- e. Bladder routines

Comments included that independent cathing provides more freedom for activity during the day, otherwise there is a strict schedule needed for the person with SCI and his caregiver, which impedes activity, especially any distance traveling.

*Spouse: "(Cathing) is the number one deterrent in the way we live our lives."*

- f. Regimentation Training

Caregivers commented that being trained in the military/police force to be regimented helps the person with SCI in adapting to the needed lifestyle changes including bowel and bladder management programs after SCI.

- g. Sleep issues

*Spouse: "I sleep in another room."*

*Spouse: "We don't sleep together."*

- h. Associated Feelings, Perceptions that Caregivers Experience

- i. Grief

One wife caregiver was grieving the death of her husband; another was grieving the loss of life's activities before his wife's SCI.

- ii. Isolation

Caregivers expressed a sense of isolation and a need for a network of friends who understand.

*Spouse: "When you're stuck in your house and in this little world...and you want to go do something and you can't..."*

*Spouse: "...to be more open with my friends that there are problems...that ...this is hard..."*

- i. Expressed Needs

## DOD Project: Summary of Salient Issues from the Caregiver Focus Group

April 13, 2016

Sunny Roller, M.A.

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- i. Better rehabilitation education from hospitals, social workers needed on care techniques

- ii. Respite Time

*Spouse: "I lose a little bit of time for myself...needing to get away, but can't get away..."*

*Spouse: "I can't go home (like paid caregivers). I'm home, you know and how do I not...take my frustration back out on...?"*

*Spouse "I have a group of friends...we go for three days every year up north...that's my vacation...those three days".*

*Spouse: "my going upstairs was ...my break."*

More structured respite time was a strongly suggested solution to these caregiver issues of stress and isolation. Group members suggested they would like to go to caregiver meet-ups at Starbuck's or to an organized caregiver camping retreat for a weekend.

### 2. Quality of Life/Relationships

- a. A high quality of life was associated with the ability to actively participate in the community with one's spouse who has SCI.

*Spouse: "...quality of life...to be active still."*

- b. Effect of Caregiving on Relationship with Care Receiver

- i. Strong sense of closeness; there is a bond, connection that caregivers develop with those they are caring for.

*Spouse: "So it brought us closer together, yes, but 24/7 with a spouse isn't the most ideal thing..."*

*"Others said, 'we can see how unified a unit you are now, and you didn't seem that way before.'"*

- ii. Dual roles as spouse; sexuality combined with caregiver role gets blurry and confusing

*Spouse: (When helping with bowel and bladder function) "...a spouse just doesn't do this...you're intimate. You know your spouse's body, but you shouldn't know it this well..."*

*Spouse:"( since her injury) I slept upstairs...she slept downstairs...you lose a lot of that intimacy..."*

*Spouse: "We were lucky we had each other...he was my mental caregiver; I was his physical caregiver..."*

## **DOD Project: Summary of Salient Issues from the Caregiver Focus Group**

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During the course of the caregiver focus group it did not become clear how involvement in delivering bladder and bowel treatments differs depending upon whether caregivers are family members. This was not discussed in detail. It was clear that caregiver spouses were under pressure to perform around the clock, whereas paid caregivers could separate and go home. It was also clear that dealing with bowel and bladder issues could affect quality of life for persons with SCI and their caregiving spouses. Well-organized management regimes are learned over time and crucial to maintaining the highest quality of life.

## **SUPPORTING DATA**

Supporting data accompanying this final report include:

- Tables of Sample Attributes
- Means and Standard Deviations for Study Measures
- Bladder and Bowel-Quality of Life Matrix
- Response Shift-Quality of Life Matrix
- Response Shift-Quality of Life Thematic Analysis
- Complications Matrix
- Caregiving Matrices



### Attributes of the Caregiver Sample

Attribute	N	%
Gender		
Male	3	15.0
Female	7	85.0
Race/Ethnicity		
White Non-Hispanic	15	75.0
Black Non-Hispanic	2	10.0
Other	3	15.0
Age		
<= 45	10	50.0
46-59	7	35.0
=> 60	3	15.0
Marital Status		
Not Married	8	40.0
Married or SO	12	60.0
Level of Education		
High School or GED	7	35.0
Associates Degree or Certification	4	20.0
Bachelor's Degree or higher	9	45.0
Type of Caregiver		
Home Health Agency Employee	3	15.0
Independent Contractor	5	25.0
Family Member Unpaid	7	35.0
Family Member Paid	3	20.0
Other Paid	1	5.0
Provide Services to Multiple People		
Yes	7	35.0
No	13	65.0
Provide Assistance with Bowel and/or Bladder Management		
Yes	18	90.0
No	2	10.0
Annual Income from Caregiving		
None	7	35.0
\$10,000 - \$19,000	4	20.0
\$20,000 - \$34,999	4	20.0
=> \$35,000	4	20.0
Unknown	1	5.0

### Attributes of the SCI Sample

Attribute	N	%
Gender		
Male	32	80.0
Female	8	20.0
Race/Ethnicity		
White Non-Hispanic	33	82.5
Black Non-Hispanic	4	10.0
Other	3	17.5
Age		
<= 45	12	30.0
46-59	15	37.5
=> 60	13	32.5
Years Since Injury		
<= 1	10	25.0
10 – 25	14	35.0
> 25	16	40.0
Served in the US Military		
Yes	22	55
No	18	45
Marital Status		
Not Married	21	52.5
Married or SO	19	47.5
Level of Education		
< High School	2	5.0
High School or GED	16	40.0
Associates Degree or Certification	6	15.0
Bachelor's Degree or higher	16	40.0
Neurological Category		
Incomplete Paraplegia	6	15.0
Complete Paraplegia	11	42.5
Incomplete Tetraplegia	17	27.5
Complete Tetraplegia	6	15.0
Etiology of SCI		
Vehicular	19	47.5
Sports	5	12.5
Fall	8	20.0
Violence	4	10.0
Medical	4	10.0
Receive Caregiver Services		
Yes	31	77.5
No	9	22.5
Annual Household Income		
< 25,000	7	17.5
\$25,000 - \$75,0	20	50.0
> \$75,000	10	25.0
Unknown	3	7.5

Means and Standard Deviations (SD) for Study Measures

	Mean	SD
QOL from Semi-Structured Interviews	7.33	1.92
PROMIS Global Physical Health T Score	42.01	6.53
PROMIS Global Mental Health T Score	50.51	8.70
PROMIS Anxiety T Score	46.79	9.45
PROMIS Depression T Score	45.65	9.79
PROMIS Fatigue T Score	48.19	8.82
SCI-QOL Bladder Management Difficulties T Score	47.70	8.75
SCI-QOL Bladder Complications T Score	45.58	6.49
SCI-QOL Bowel T Score	46.94	7.14
SCI-QOL Positive Affect & Well-Being T Score	54.82	8.64
SCI-QOL Ability to Participate in Social Roles & Activities T Score	46.12	5.84
SCI-QOL Satisfaction w/ Socl Roles & Activities T Score	46.66	5.46
Spinal Cord Injury Lifestyle Scale Genitourinary Subscale	10.692	2.97
Spinal Cord Injury Lifestyle Scale Neurological Subscale	18.108	6.40
Spinal Cord Injury Lifestyle Scale Psychosocial Subscale	7.436	1.07
Total Spinal Cord Injury Lifestyle Scale Score	70.829	9.97
Quality of Caregiving Measure Importance Score	41.194	3.32
Quality of Caregiving Measure Caregiver Score	14.258	1.59

**Table 1: QOL Contributors/Detractors and SCI-Related Issues Affecting Bowel and Bladder**

Participant	QOL Rating	OOL Contributors/ Detractors	Bowel Practices and Issues (+ and -)	Bladder Practices and issues (+ and -)
<b>UM-005:</b> F/W 35/19 yrs Vehicular P/I single Employed, Living alone	7.5	I'm pretty happy...how independent I am... feels great...thrilled with the way my life's going... completely self-sufficient. Still not walking as good as I would like...sometimes wish I had more help. Do feel it would be easier if I had a partner to help me with things. <i>[Impact of B&amp;B dysfunction on life goals]</i> No, it really doesn't because I'm very lucky that I've been able to do everything that I want to do <i>[Impact of B&amp;B dysfunction on sense of the self]</i> I think it causes a little insecurity...not on the surface ...maybe on a deeper level	With my bowels I feel I'm in pretty good shape. Constipation...A couple of years back I did start having more problems with constipation, but now that's pretty under control...been like months and I haven't had to take anything like that, so I'm really pleased right now I would say for me it's gotten better. With the sensation for my bowels, for example it's pretty normal right now.. <i>[when away from home]</i> Well, I guess I may try to schedule my time me, if I go somewhere.	Self-intermittent cathing....typically I try not to cath because I have gotten UTIs and stuff ..so I do try to void by myself. If I feel like I keep having to go every half hour and I'm not completely emptying then I will cath because I know that I need to fully empty. I would rather not catheterize, but I am not a able to empty on my own in the toilet without catheterizing...I can't get all of the urine out...
<b>UM-008</b> F/W 63/22 yrs. Fall; P/C married retired Spouse(S)0	7.5	...was pretty successful in career; Financially, I'm probably fine. Would love to be walking; to do more physical things; Family and friends are very important to me; Frustration of not being able to do certain things you want to do. <i>[impact of B&amp;B dysfunction on life goals]</i> can't say that it does any more than being paralyzed does. <i>[Impact of B&amp;B dysfunction on sense of the self]</i> Always been fairly ...shy. You...just ask for help when you can't get to facilities... I was ...always very independent and it just makes it harder.	I never had as much problem with my bowels ... I do find that if I take a probiotic... helps me to be more regular. I think that does make a difference. Before I did that there would be times when I would be sort of constipated... .because you don't get as much exercise... do have an FES bike and I think that helps...I think it definitely helps my bowels function ...you're just more regular getting exercise and you're you know that whole bottom part of your torso it's moving as your pedaling the bike	I've gone through menopause so I no longer had periods but when I did that was the hardest thing in controlling my bladder. I never knew exactly when this was going to happen but I would retain water. So I wouldn't have anything and then all of a sudden it was like the damn broke. That was the hardest to be able to figure how to time that and deal with.
<b>UM-009</b> W/M 50/28 yrs. Vehicular P/C Married employed sp/so	8	<i>[Impact of B&amp;B on life plans]</i> ...I remember on some questionnaires they asked: If your bladder program stayed the same the rest of your life would you really be happy, really sad... indifferent ...have a hard time answering that because I'd be really happy if it didn't get worse, but it's still kind of problematic. <i>[impact of B&amp;B on quality of life]</i> It does have an effect on how I live. Other than not being able to use my legs those are the issues that do have the greatest effect on how things work for me day to day... It's something that I always have to worry about.	...I'm fortunate in that it's not worse than it is. I understand some people have a lot more problems with bowel accidents....I've been getting Botox injections..... Since I've been doing that it's been very beneficial as far as not having accidents and my infection rate has gone down, so that's helped quite a bit.	I've had some problems...with bladder infections lately but it seems that I've been able to adapt or control the situation enough where it doesn't really create a lot of problems for me. <i>[regarding cathing]</i> I don't get hung up on it. It's irritating and I take care of it and move on. I don't try to sup-press it I guess. I've got other stuff to worry about.

**Table 1: QOL Contributors/Detractors and SCI-Related Issues Affecting Bowel and Bladder**

Participant	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>UM-010</b> W/M 35/16 yrs. Violence P/C Employed; parent	<b>6</b>	<i>[SCI injury]</i> ...my whole life was turned around ... still has its affects to this day.... not hopeless-not stuck. Still got options...fairly healthy...good friends...fairly independent; good family, opportunities. Got disappointments...regrets ... Doing better than average. <i>[Re: Life goals]</i> ...set me back some years...financially....can't have a ... structured job...and be super dependable...bowel and bladder thing has prevented me from .putting that extra effort...to be a real responsible on time employee. My attendance is...not great and I'm late a lot. <i>[Sense of the self]</i> I a think it's really affected my self-image...it's made me look at myself more realistically...	... you know what to expect when you can't walk. You know your limitations but with your bowel and bladder, I mean you can go out one day just feeling great, thinking "Okay, I'm going to go out and do this and this and this and this," and then like 20 minutes later you like start sweating and you're like "Oh God, I'm going to shit my pants.. can't do anything, and you've got to turn around and pretty much call everything off. And that sucks, you know ... if I defecate myself then I'm like "Oh, this is the worst," and I just get through.	... If it's my bladder I'm more used to that and I can kind of deal with it. If it's really bad and I'm totally soaked it's like "Oh God" and I try to avoid talking to anybody. I still get very embarrassed about it, you know, it's kind of dumb but I guess I'm human. So that, and yeah, , and you just get pissed off and...when panicky that makes your bladder so much worse
<b>UM 012</b> W/M 56/12 Vehicular T/C Retired- disability Spouse	<b>5.5</b>	...Problem with quadriplegics...you don't know you have the infection until it's full-blown... where it will put you in the hospital, and that has happened...As it is, what life I do have is so reserved and so scheduled...that's not life. <i>[B&amp;B dysfunction on expected life course]</i> I'm much more reserved because I don't want to get sick. That's really what it comes down to... I don't see myself too far down the road. I don't look at the future the way I used to anymore. <i>[Most satisfying]</i> Waking up...when I'm able to spend time with my wife and ...and do things with her	I have had some accidents, bowel accidents, and it's usually due to having to take a number of stimulants because maybe I'm fighting an infection and you just...sometimes those stimulants don't give you a clue of when it's going ...when you're going to have a bowel movement. And so I've been in my chair and had bowel movements. I've been in bed at night and had bowel movements and not know. Thank God they're very few and far between.	The many prostate infections that I get in a year, and especially over the last 13 years, they're very difficult to battle and if I wasn't in the condition that I am-- no telling how much more I would have been in the hospital having to battle them with IV antibiotics. ...because having the straight cath or use a Foley from time to time when I'm away I get a lot of infections...prostate infections...I continue to struggle with quite a bit. And that makes it more difficult to enjoy life and to get away.

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Participant	QOL Rating	OOL Contributors/ Detractors	Bowel Practices and Issues (+ and -)	Bladder Practices and issues (+ and -)
<b>UM-013</b>  F/B 63/36 yrs Vehicular T/C  Divorced Retired/dis- ability  Adult children	9.5	...now totally independent...community work ....own my own company involved in organi- zations ... sports...live a full life...goals.. Would .like a day when I don't have to do anything... [QOL] making those adjustments where you can still continue to have a great quality of life. [bladder infection on QOL?] Fatigue...makes me drag a <i>little [ability to be romantic]</i> I don't think it impacts...[ <i>Life goals?</i> ] ...contemplating how soon it's going to be before I have to have a personal .assistant. [most satisfying...peer mentoring]...least satisfying...having to cath...	I've never really had any bowel problems be- cause like I said, I do my bowel training...I'm still doing everything independently myself, my bowel training...It's taking me sometimes a little bit longer and because of the age, because of the fatigue because it really wears on my shoulders	I found out that my bladder was good and here were no stones or anything like that, That was a relief...talked (to doctor) about ... Botox because... not an option to do an in-dwelling or surgery...continue doing the things that I do and still take good care of my situation. It's just a matter of dealing with the bladder infections, need to be sure that I cath and I go no more than five hours and then make sure that I don't cath every two hours all the time and that kind of stuff. So it's just a managing it better. That's been the thing that's been
<b>UM-014</b>  M/W 64/41yrs Violence T/C  Married Retired- disability  Spouse/SO	9	[Big change] The depression was the worst part ....when I turned 50 I had it real bad....when I turned 55 it hit me...a little bit worse but it didn't seem to last quite as long. The first time it lasted about 6 months. The second time it lasted about four months....I've had small depressions before. .I get out and do things. That's how I stay away from depression [ <i>Impact of B&amp;B dysfunction on  QOL</i> ] My retirement plan completely turned around.... [ <i>future goals</i> ].. .continue what I'm doing..[most satisfying] Being able to go out and visit with people. [ <i>Not satisfying?</i> ] Not being able to go out...	[when] I'm planning on an event or something I...put a leg bag on...normally I would do intermediate cathing.]  Nothing specific about Bowel care....has 6 caregivers who provide 24 hour care.	Nothing specific about Bowel care....has 6 caregivers who provide 24 hour care.
<b>UM-017</b> M/W  43/24 yrs T/C  Single Employed  Spouse/SO	10	<i>Importance of intimacy/sexuality</i> It's as high as they get] ( <i>NB. Extensive discussion</i> )[Impact of B&B dysfunction on life goals].things that you thought were out the window, you start looking through a different window....took me two years...didn't happen overnight....So I started changing my ways and waking up to things ...my mom kicking me out woke me up. [ <i>Future  goals?</i> ] Oh, retired. Five years down the road, I'm hoping to be in the same health that I'm in today which is good, but the last couple of years have just been tremendously wonderful, very good, very up-lifting. I've purchased a home... got new jobs.	[Speaking activities with newly injured] I've explained my bowel routine and they're like this. I'm like this is why I'm here, this doesn't go away, never. I've cried, I've begged, I've done everything, it will not go away.	...cathing a big let down.... I practiced and practiced, figured that shit out. [ <i>advice...to  someone who's... experiencing B&amp;B  complications?</i> ] Pay attention to the body. Pay attention to their aide and what is taking place at that moment. Be open.

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Participant	QOL Rating	QOL Contributors/ Detractors	Bowel Practices and Issues (+ and -)	Bladder Practices and issues (+ and -)
<b>UM-018</b> <b>M/Hisp</b>  30/10 yrs Sports T/I  Married Retired Disability Spouse/SO	<b>7</b>	<p>The thing is I'm happy with my life. I'm not sitting in the chair waiting for the cure. If something happens and I get to walk again or my bladder and bowel work again, I'm happy, but my quality of life is excellent....so I find other things to do.....<i>[impact of B&amp;B dysfunction on the social life.]</i> It really hasn't unless I have an accident of some kind, to be honest. <i>[Impact B&amp;B on sexuality]</i> ...it really doesn't....intercourse is impossible... with the indwelling catheter....<i>[impact of B&amp;B on expectations]</i> didn't really have that many before injury..<i>[goals 5 years]</i> I hope to be alive and preferable sore free</p>	<p>Ever since I got home I was doing the every other morning bowel regimen because it seemed like a better option than doing it every morning just because if I did that I would be changed to the house.... Like when you have bowel accidents on a trip or something you try and figure out what caused it and you make a note of it, chalk it up to experience and..... especially my bowel..</p>	<p>So there's that and all weekend she has to drain my leg bag when it gets full, so there's also that. She's qualified in all of those things. But I think it's better that she have to do that and we keep our weekends than having to have people come in during the two days where Robin doesn't have to work or deal with anyone.</p>
<b>UM-020</b> <b>F/W</b>  52/17 yrs. Vehicular T/C  Divorced Employed Alone	<b>9.5</b>	<p><i>[re-adjustment to SCI]</i> ...normal process of desensitization....human adaptation....process of adaptation...a little bit of that, too, having to face the reality that shit happens...<i>[impact on QOL]</i> very little because I find substitutions shifting what's important to you and what you value, so. <i>[Impact on life goals/expectations]</i> No impact whatsoever. I have 24-hour nursing, I have the flexibility to go where I want when I want. <i>[Impact of B&amp;B on expectations]</i>. I've actually exceeded my expectations of what I thought my life would be.</p>	<p>I think spinal cord injury really does force some life changes on you. It's really hard to go out late at night with the bowel program because every other night I've got something scheduled, then you have to come home at mid-night and do it... sometimes I just suck it up and say, "Oh, well. I'm going to be doing the bowel program when I get home and life goes on." No , other than the fact that yeah, I'd love my...especially my bowel. I'd love to be able to poop on my own. Poop on demand. That would be the greatest thing in the world.</p>	<p>...really impacted my life in a negative way having to do the intermittent catheterization through the urethra. When I got that indwelling catheter...gave me freedom that I don't have now. ...problem was that it is not healthy for your bladder... went to see Dr. McGuire and I talked to him about the diversion...bladder was deflated for 6 years... was able to train my bladder or stretch it so that I could hold the 500, 600 ccs ... So I would recommend. .urinary diversion to any-one who is able to afford it.</p>

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Participants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>UM-021</b>  F/W  55/1yr Medical P/I  Married Retired-age Spouse/SO	<b>9.5</b>	<i>[impact of B&amp;B on social relationships]</i> Not so much ...now. In fact, it's almost like overkill. Everybody wants to, "Can I take you here?" <i>[B&amp;B dysfunction on sexual activity]</i> husband has health issues...when you have a tube you do not want someone laying on top of you <i>[Impact on sense of the self]</i> But for my sense of self, I'm still very confident....I can still do things... I'm here still. I'm living at home with my kids and my husband. I can't ask for much more than that. <i>[Life Goals?]</i> "Well, my life's goal is to be happy and healthy and I am". Have a positive outlook, positive attitude.... Don't give up. I still have bad moments every now and then... Acknowledge that it is hard. But then...acknowledge that you're still here.	We bought a four-legged, padded stool to put over the toilet...I transfer from my w/c onto the stool. I have gloves... little gel packs and I use baby wipes a lot just for cleaning myself. I do digital stim. Sometimes, I'll do a second digital stim...do that 2/3rds of the time ... And. A third one if things are going slow. Today, it took me 30 minutes for anything to happen. I go every day...And I have had no accidents... It's still kind of a soft stool. It's not real firm ...I don't really know who you talk to about tweaking it...I was down at another therapy in Atlanta that they thought it would firm up more but they also said, "This could just be you.... the bowels have greatly improved.	[In hospital] they were trying to get me to self cath...could not sit up really...didn't have the control...couldn't hold my upper body... needed to be cathed about every...two to four hours....Ultimately...Dr. C put a super pubic tube in me. I still have it right now to this day. My biggest holdback... the ease of the bag...as I've been going to a lot of therapy [Georgia]... so I asked her [Dr. C] if I could keep this super pubic tube until I'm done down there, which, I'm not sure how long it will be...And it will be done in about a month ...they're going to still keep me working there. Then, I'll have to decide to have it taken out if I want then or not. [no complications]
<b>UM-023</b>  M/W  57/1yr Falls P/I  Divorced Retired/age Parent	<b>5.5</b>	Well, I'm sure it's disrupted my life some. But I still do the things that I used to do; it just takes me longer to do them. <i>[Before/after Life changes]</i> no fishing this year out in Lake Erie. If I wasn't injured, I'd. ..be out in the woods, right now, because this is cross-bow season. Gun season opens up Friday... I'm going to be out there Friday. It's going to be a long recovery... Don't look back because yesterday's already gone and you can't do anything about yesterday, but you can do something about tomorrow.	<i>[Impact of bowel dysfunction]</i> ...when I sit and when I stand up that's when my bowels release gas. We had company over the other day and they got ready to leave and they stand up. I can't stand up and shake somebody's hand because I might let gas rip out.	<i>[Nothing specific about bladder, however, the following is pertinent]</i> . I don't know... whether my bowels and my bladder and everything are going to come all the way back. It may not.. Then again, another six months from now I might be able to walk in here and say, "You know what? They did. They're all working fine now and I'm great, man..." "You'd better give it all you've got, 100% because there are no do-overs...
<b>UM-030</b>  F/W  45/1yr. Falls  P/I  Married Retired/ disability Spouse//SO	<b>5.0</b>	<i>[Impact of B&amp;B dysfunction on expectations/life goals]</i> I wanted to move up in Wal-Mart.....that's the only thing it crushed.... I would like to eventually talk about spinal cord to people and let them know that your life's not over because you're in a wheel-chair. <i>[Impact of B&amp;B on sense of the self.]</i> It makes you mad because it's like why can't I hold it?... it just makes you feel helpless sometimes ...I can't hold, I'm in diapers... So it just makes you feel weak in a way... <i>[What would help make you more happy?]</i> Being able to get out more and go see people, get my mind off of things. Being able to go out and watch birds, watch nature stuff.... Clean my house.	But that's the only thing. Now my bowels are pretty much--they got me on a bowel program where they were doing suppositories, but now I can go on my own. It just depends on the bowels itself. But my bowel it isn't that bad. It's once a day and usually it's probably an hour after I eat or something like that now.	it's...the bladder that really bugs me me....I can't go out for a very long time... discouraging too because ...you've got to sit there and always worry when do I have to go....straight cathing and we make sure we do it every four hours, day and night, but with me feeling it sometimes it's a little bit sooner... right now with the bladder problems I'm having we don't cath every time I have to go because I'd never make it to the bathroom. I never make it to the bed. I would like to get it under control where I can do it myself and be out more.



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Participants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>UM-038</b>  F/W 46/1yr.  Vehicular P/C  Divorced Retired- disability Spouse/SO	<b>5.0</b>	<p>If I had my legs I wouldn't have this problem ...my dream got taken away and my husband's did, all of them...I can't jump in my vehicle, go anywhere. I can't drive, my vehicle was totaled and I'm scared to death to drive; I'm scared to death to even be in a car. I worry that my insurance company isn't going to fix my house or paying them [aides] to take care of me ...but, right now, they haven't got paid nothing. <i>[Impact of B &amp; B dysfunction on expectations]</i> Well it's as good as it's going to get I mean right now I'm kind of stranded....It might get better you know. <i>[What kinds of expectations are important?]</i> Walking, being able to drive, ride a bike, doing things Id used to do.</p>	<p><i>[Going to the bathroom]</i> I do like a diaper... when a baby poops in a diaper. Basically the same thing ...Well it's embarrassing, but it's got to be done.. Can't get in the bathroom...we wash in the bed, brush teeth in the living room ...wash up in the bedroom. I wish I got a toilet but my house isn't ready so we do what we do to make it done. You got to do what you got to do I guess.</p>	<p>.two hour window is annoying... ,remembering that I have a two hour window. That's basically what you got to be careful for. [bladder care] I had a Botox done so now I'm not having no leakage, I can go about three hours before cathing a little more sleep at night; [When out in public] We go out in the van [re: botox] ...The day I went in for, because I was leaking so much and cathing so much, I went to my doctor and they did an ultrasound and I couldn't even hold 100 cc's without wanting to go pee again. So she said "I know exactly what's going on with you," she said "Your bladder is having problems, I can help that." And I'm like "Okay, let's do it."</p>
<b>UM-039</b>  M/W  42/1yr. Sports PI Divorced Employed	<b>6.0</b>	<p><i>[impact of B&amp;B dysfunction]</i>... to me it was demoralizing, like...I've been single... divorced now for about going on five years...it's hard ...like, if you have to go you got to get to a bathroom fast. I...kept my head down...I didn't even look at women, you know, in that light... I felt less of a man... not being able to control my own bowel functions, knowing that...if when it comes to...meeting a woman. <i>[Impact of B&amp;B dysfunction on sense of the self]</i>: It affected me pretty tough at first. ...and I learned how to deal with it... learn that's me, that's who I am now, so, try not to let it affect me like I did before, you know.</p>	<p>...it plays on you emotionally and mentally when you can't control your bowel function ...and that was me, at first I... I don't think I went for about first twelve days. I had a urinary tract infection even before I got injured... and they gave me some medications, but it didn't really help and I had it when I was in the hospital...here, and they gave me some medication and it didn't really help, so I'm just starting to think, there's something up with my body where...just have to pee every couple of hours, like, pee really bad....So, that's basically the extent of my urinary tract infection...they couldn't find anything. They couldn't find anything wrong with my kidneys.</p>	<p>... at first... I don't think I went for about ...the first ten days...they had to give me catheters every day...about five or six catheters a day for at least the first ten days. So, I've been pretty regular, but it's, it's hard to... like, if you have to go, you got to, I got to go. I've got to... get to a bathroom fast because it's, you know, it's almost like I don't have any control over it. And it's like, but it seems like it's getting better every day that goes by. I get like a little bit more control here and a little bit more control there. But, you know, if I was in a car and I had to go, if I didn't get to a bathroom, I'd probably go on myself.</p>

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Participant	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>UM-040</b>  M/W  61/1yr, Falls  P/C Married Retired Disability  Sp//S0	7	<i>[Impact of B/B dysfunction]</i> I expect all that stuff to come back. That's my beliefs and my expectations for myself. I hope that I can get home and I can control that stuff so my wife doesn't have to deal with it. I'm pretty religious as far as my belief in God...so I get up every morning and just thank God that I got another day here. <i>[ B&amp;B impact on sense of the self]</i> It hasn't beat me up at all; hasn't changed me a bit. I'm down right now but I'm not out. I've been seeing so many people here get better and leave and every time somebody else leaves, I just take that as a sign that one day I'm going to be the person that leaves.	Actually I do it in the bed. I do digital stim and wear obviously gloves and lubricant, pull it out and throw it in the garbage bag and clean up.... well I can put on the glove, with me I only have use of one hand. So I had to figure out, well I can put the gloves on like this and I can take the gloves off like this, without having to have her do it for me. If I put the garbage right here, I can reach in and put everything right there,	Sometimes I have to lay in a wet diaper a little longer than I'd like to because they've got so many people to take care of here... things that I have to deal with aren't that big....I had a bag it just went into and it was easy enough to drain the bags. But then with lots of fluids, then you have to cath more because otherwise you get a full bladder you leak and you don't want that. It's a matter of tracking when you're drinking and when you're cathing, figure out a good rhythm to things to balance
<b>UM-041</b>  M/W  60/0 yr. Medical  P/C Divorced Retired-Age Alone	5	<i>[Future goals?]</i> ...haven't really thought that far ahead. <i>[Sense of Self]</i> the bowel thing....can really ... mess with your self-esteem when you have an accident, and you can smell it and you know everybody around you can smell it, <i>[Impact of B&amp;B dysfunction]</i> can't pull your own pants down,....don't think it [bladder] affected me as bad as the bowel has.... it definitely messes up your quality of life ....just adapt to the situation you're in....Everything you did was a chore... But you figure ways out. It's a little bit easier or works for you.	It sucks! <i>[laughter]</i> The bowel thing has been a work in progress... trying to get it down right and ...get it to happen at the same time every day and ...the right dose of medication so you're not too hard and not too soft and I don't know. ...I still don't have the bowel program down... having probably, at least one accident a week...I cut the Miralax out, it's been pretty darn good for me... been taken off of Senna... check my bowels every 4 hours... If I can figure out how I can do this bowel thing that would make a big difference too.	[hospital] They had to put in a cath (Foley) ...they were having ... problems cathing me. ...wound up I had to have the Coude cath... I haven't had problems cathing. [home] ...the idea of doing it was harder than the actual doing . [home] at 3:30 in the morning ...I cath myself in the middle of the night...cath every 4 hours. [Bladder function on QOL?]. pretty lucky... since they've discovered that Coude's work for me...I can work my pants down enough in my wheelchair to cath myself in my wheelchair if I have to.
<b>UM-042</b>  M/W 55/1yr, Falls  P/I Married  Retired Disability Sp/So	2	It's not a good situation here, not for my wife... I'm a surfer boy...lived in Hawaii and Florida and California. ...even before an airline job and now I'm out here and I'm broke and I have a credit card debt.. we cannot pay any more. I'm in a situation I never wanted to be in, ever. ..I have nothing... I wish I could go surf again. <i>[impact of B&amp;B dysfunction on life goals]</i> If I had everything the way it used to be, well with a freakin' job... million dollar house, lot of money in the bank, perfect health, but I just had bowel and bladder issues; I would say well that's fucked up but I'll deal with it.	...somebody told me when I first started going through this to not put 100% in everything the doctors tell you. Sometimes you've just to figure this stuff out what works for you...Well with stool softeners that I have. Got myself off a couple things because it wasn't working for me... but I've been taken off that Senna. I don't even know...I'm glad not to be taking it	God, just to be able to go to the bathroom on your own and you don't think about what a privilege that is until you lose it; but you know, that is compared to everything else in my life, that's probably the lowest thing on my list. But as far as my bowel and bladder issues, they are not keeping me from doing anything. My physical abilities, where we live, and money; but the bowels and the bladder is not affecting me as far as doing <i>[Does not directly discuss bladder issues or it's specific impact on QOL]</i>

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Participant	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>UM-043</b> M/W 33/1yr. Sports T/I Divorced Employed Parents	<b>6.5</b>	It's starting to seem very difficult...it's difficult but it's just the whole change of life... You don't really expect to ever experience it...you kind of lose all your modesty at some point ...That was one of the most difficult parts was coming to the reality that you'll never have that control. Every other day, I have a nurse come in in the morning for bathing and dressing	[ICU] They kind of explain to you that this is just the way it's going to be. And...you go into rehab and then you start doing your bowel program and stuff like that...The 1st time you have an accident ....you're lying in the hospital bed and you don't understand what's going on. You feel like you need to apologize for it... every other day I do a bowel routine, and the nurse does that for me...I don't have many accidents right now. I'm wearing regular underwear now...That's been working out really well for me	....you get cathed every four hours or every three hours, people see that...I had a pubic catheter surgery, so I wouldn't have to be cathed every four hours....now I wear a life bag....Every four or five hours... need to empty the life bag and then at night I put in a bigger bag that hangs off my bed. It's obviously a pain because ...I need someone to empty for me and to switch the life bags and other things like that. I'm hop-ing in the future, I'll be able to do that myself.
<b>UM-044</b> F/W 27/1yr. Medical T/I Single Temporary Disability Parents	<b>7.5</b>	...the biggest thing is just I got to plan my day now every move that you're going to make.... as a young woman. like I can't be intimate or anything... because I don't know what's going on...I definitely have my moments ...I just like cry and just an emotional wreck and just mad at the world, and then other days I say, "Okay, this is it. I mean there's nothing I can do about it. <i>[Least satisfying]</i> The bladder and bowel and the not walking and doing just simple things <i>[Impact of B&amp;B dysfunction on sense of the self]</i> you just kind of feel like a big baby <i>[future goals in five years]</i> I would hope to be cathing myself...even maybe bowel program by myself....eventually go back to work to have that sense of you know, you're contributing to something, or	It's totally different. Like even just the smallest things like sitting on the toilet, taking a poop... It's totally different...or even just like wearing under wear ....sometimes I stay home and let her go out and then the whole bowel situation... I have no control over it so I mean I do a program every night of a suppository...but again, I have to rely on somebody else to do it...and I feel bad for her, but I have no control over it during the day where I don't – I mean I could be shitting my pants right now and I don't know it.	usually first thing in the morning I get cathed by my mom... if we're going to therapy and then usually...she'll cath me at the last minute. ...she'll cath me once during the middle of the day. It's usually like you know, 4:00, 5:00, 6:00...and then she'll cath right as I'm going to bed. I have to worry about where I'm going and what time because I have to be cathed every six hours...if I'm out and about if there's going to be a place where I can get cathed at ...So I kind of – sometimes I stay home and let her go out and so I got to work with other people's schedule

**Table 1: QOL Contributors/Detractors and Issues Affecting Bowel and Bladder**

Participants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA-002</b> M/W 45/20 yrs. Vehicular TI  Married Employed Spouse/SO	<b>8.5</b>	<p>[Life change] What didn't change!...Career structure changed...,had to learn how to drive, dress all over again, get around the house. <i>[Community participation]</i> Make sure there's a place...to go to the bathroom [Impact of SCI on life goals] Was a career military guy...now a data geek at a billion dollar company. <i>[Sense of the self]</i>.I'm much more empathetic and understanding... much greater respect for life and people ...much more cautious...tend to keep my distance from people a lot more...worried that I am to have an accident and smell like urine.... makes you more shy.</p>	<p><i>[Bowel Management]</i> I do it in bed. I do digital stim and wear obviously gloves and lubricant, pull it out and throw it in the garbage bag and clean up. Initially you start out using the suppositories and I didn't like that, because then I did have the accidents and what-not. So I tried going without them, making sure I had a high fiber diet and what-not.. I found I had better luck with that. <i>[Bowel complications]</i> Haven't had any complications....I've been very fortunate ... no hemorrhoids or constipation ....Never had an impaction.</p>	<p>I don't have to reuse catheters, which is lovely Used to be that they'd give you four a month... had to reuse them and then about two years ago... you get 200. <i>[Complications]</i> UTI's and kidney stones...which all go hand in hand with intermittent catheterization...That's even gotten better...the stones are... a booger. I had to get lithotripsy I don't know how many times to get rid of those, but the lemon water and whatnot seems to help curtail those a little bit, not 100%. You can take magnesium, or some other supplements. Had them twice....also had skin breakdown.</p>
<b>VA-003</b> M/W 35/13 yrs.  Vehicular TC Married Retired/ disability  Spouse/ SO	<b>8.5/9</b>	<p><i>[Life change]</i> Oh it's a complete change of life. I mean you go from being self-sufficient and doing what needs to be done to depending on people around you. <i>[Impact of B&amp;B dysfunction on sense of the self]</i> It hasn't changed me. I mean it is what it is. <i>[Impact of B&amp;B dysfunction on ability to do things]</i> With the system I have now, absolutely not. I can travel as need be and spend a whole day out on a dive boat. It doesn't matter. <i>[Impact of/B &amp;B dysfunction on Life goals/expectation ]</i> It really doesn't have an impact on me anymore.</p>	<p><i>[Bowel Routine]</i> don't even want to think of if I didn't do my bowel care in the morning what would happen.... in the morning I'll allot so much time for bowel care, before I leave the door, before I can get up and get cleaned up. Yeah I mean it's scheduling and routine. There's some, I mean you get your bouts of constipation occasionally if you don't drink enough water or depending on what you ate that day or whatever. It's a learning curve. You just got to figure out what works for you and stick with it.</p>	<p>[Bladder Routine] when I was first injured we were doing the intermittent catheter method for bladder management. It's every four hours. It's just an inconvenience. It really is. So as time progressed I opted for a urostomy which is really a lot easier way of maintaining it as far as I'm concerned. I was getting UTI's all the time. I was getting bladder stones. It was complication after complication....[now] gotten very few UTIs maybe once a year</p>
<b>VA-004</b> M/W 43/10 yrs,  Sports PC  Divorced Retired Disability  Alone	<b>9</b>	<p><i>[Impact of B&amp;B dysfunction on relationships]</i> Not that much at all. At first, yes, definitely yes...I've come to the point where I'm going to live my life. If I have an accident, it happens. <i>[B&amp;B impact on sense of the self]</i> ...not at all at this point. At first, yeah it did affect me But now, I know it sounds weird, but I basically don't even consider myself in a wheelchair now...I guess I don't feel uncomfortable about approaching people, communicating with people, interacting with people. Like I said, it just doesn't really bother me anymore.</p>	<p><i>[Advice on bowel and bladder complication]</i> I've come to the point where I'm going to live my life. If I have an accident, it happens. ... not to let it control your life. If it happens, it's going to happen. Prepare yourself for it by carrying a backpack with a change of clothes in it and stuff to clean up with.</p>	<p>... I guess try and become more in tune with your body and if you know you're going to go out somewhere try and do your bowel care before you go out. You know, just a common sense approach to it....I think it was just trial and error.</p>

**Table 1: QOL Contributors/Detractors and Related Issues Affecting Bowel and Bladder**

Participant	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA--006</b> M/W  57/36 yrs Vehicular PC  Divorced Retired- Disability  Alone	<b>7.5</b>	[Cleveland VA] huge ward of...spinal cord injured people...most of them were worse than me. So I started thinking, I could definitely be a lot worse off ...started thinking about... working with what I had [ <i>B&amp;B dysfunction and sense of the self</i> ] I guess I feel stronger in a way. You know just having to deal with a lot more than I've ever had to deal with, or that the average person has to deal with as far as that kind of stuff. [ <i>B&amp;B dysfunction on life goals</i> ].The big things would be the wife and kids, the retirement where you're traveling all around the world and visiting new countries and things like that would be a scary thing.	[ <i>Impact of bowel on QOL</i> ] It's a significant impact, It is a significant change in lifestyle that you have to make allowances for... whether it's putting on a diaper, that's one of the things I guess I was alluding... You know it's like, what will they think? I don't know. Is that going to affect me? It's something I think about ...I'm not sure. I know I was at the bar one time where it was the waitress that was bending over to pick up something that was on the floor and my pants were dropping a little bit and she said, "Oh, you have a diaper". Then she felt real bad, she just, it just surprised her and it came out of her mouth, that kind of thing.	Well you try to keep things covered as much as you can. I had to do it on plane once, with my first wife, before we were married, we were flying to Hawaii. Used the blanket, she took the bag and went and emptied it for me;
<b>VA008</b> M/B  48/26 yrs  Vehicular P/C Married  Retired/age Spouse/SO	<b>10</b>	[ <i>Impact of B&amp;B dysfunction on QOL</i> ] It's a significant impact, It is a significant change in lifestyle that you have to make allowances for....whether it's putting on a diaper, that's one of the things I guess I was alluding to if I were to, ..., if I was to go and see some cute girl at the bar and ...you're wearing a diaper. You know it's like, what will they think? I don't know. Is that going to affect me? It's something I think about [ <i>Secret to success</i> ] People, they say I'm the strongest one... maybe part of that is I don't want to let them down. I just want to show them that I can do it. ..its an independence thing...you want to be able to get along on your own...and that you're still able to enjoy life.	Because earlier I was dealing with it and it was hard for me, I didn't come outside much. I didn't want to be around people much. I just stayed in the house a whole lot. Because you never knew when something (bowel?) was going to happen. It's like wow, do I have to use the bathroom? I don't know. Once I learned my body and accepted that this is my life, that's how I dealt with it. You know, got over the embarrassment part.	Well there was a moment. I'll tell you one. There was an incident where I was in bed and I had just peed all over myself. I actually picked up my wheelchair and I threw it across the room. I sat in bed and I actually cried. I was like why? Why is this? Why is this happening to me? At that point, the tears turned to laughter. And people, I tell this story all the time, and people say well why did you start laughing? Because now I'm done crying and I'm laughing because now I have to figure out how I'm going to get my wheelchair that's across the room. So I have to get out the bed on the floor and slide across the floor to get in my chair.

**Table 1: QOL Contributors/Detractors and Issues Affecting Bowel and Bladder**

Participant s	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA-011</b> M/B  48/16 yrs. Vehicular P/C  Retired/ disability  Sp/SO	<b>9.5</b>	<p>I grew up in the church... raised in a Baptist church...it was just a spiritual journey for me .Why me? ...why not me? So it was a journey of deep introspective examination of myself and who I was as a man, as an individual... Your network of support, your family, that's so critical. [Re: intimate relations-Extensive discussion -not included here] [<i>Influence of the Military experience.</i>] Yeah it does, in my opinion, because you are brought up in a structure in the military with discipline and a lot of spinal cord injury is discipline and structure, sticking to a routine. And those are the two big traits that come out of the military.</p>	<p>...always used suppository to manage my bowel. I used to do it every other day and sometimes go two days without having a program. But I was running into some problems... had some accidents ...That certainly creates a lot of frustration...My remedy to that was just to go to an everyday program. And that's been pretty much how I've been managing that...part of the source of my frustration with it is the dependence on someone else, even though it's my wife. I would rather her not have to do that... So recently I'm experimenting with just doing it all myself to see</p>	<p>...when I first was injured, I did not cath. I still had sensation. I could feel when I had to go... used a condom catheter ...years later had autonomic dysreflexia...now uses intermittent catheterization...made a big difference...because it has allowed me to manage my bladder much more regularly...cut down on urinary tract infections. I had to find the right type of equipment to be able to use with my limited hand dexterity I do my own bladder routine.</p>
<b>VA-012</b> M/W  56/27yrs.  Vehicular P/C Single Employed Other	<b>9</b>	<p>...yeah you want to walk again but if you could get control of the bladder and bowel again, to me that would be awesome. Because that controls so much of your life with the spinal cord injury [<i>impact of B&amp;B on relationships</i>] <i>you do lose a lot of friends...can't get in their bathrooms... accessibility... design of the home...an issue....future goals?</i> .working ...not full time.... my goal is to continue to volunteer and give back [<i>Impact of B&amp;B on sense of the self.</i>] It has redefined it. I've learned a lot about myself. ...been a positive experience</p>	<p>And then the bowel, finding out I had to do dig stim to bring it down was an eye-opener...There's a lot that goes into getting you to that point. When I explain all the little things that go with a spinal cord injury they're always like you're kidding me.... blown away by the experience...the bowel has been the biggest challenge for me in the almost 27 years .. kept having these accidents ... it turns out I had bacteria build up in my small intestines....they gave me some medication and that's worked well....found that I have to do the bowel program daily</p>	<p>And all of a sudden they said you're doing this and she gave me the catheter and I go, what do you want me to do with this? So she, when they explained how the process worked I was like you have got to be kidding me. I have got to insert this in? ...Like the signal when you know you have to go to the bathroom, you take that for granted but I would love to get that back. When my bladder is full and little things like that</p>
<b>VA-013</b> M/W  56/37 Falls TI Divorced Retired/age  Lives alone	<b>8.5</b>	<p>[<i>Impact of B&amp;B dysfunction on QOL</i>] For me, it has had little impact on my quality...in a negative way... I've had such a fairly smooth transition. I have the network of support that I need In a positive way it's been great...good bowel program...system of support....[<i>5years down the road</i>] working on my classic cars... few vacations....I'm pretty content. [<i>Most enjoyable</i>] free time... want to use hand-cycle ... want to get myself back in shape really like my job and like doing what I'm doing. [<i>least enjoyable</i>] -bowel and bladder/</p>	<p>I used to go every other day and then I changed it from Monday, Wednesday, Friday with the week-end off.... it's like having a day off. You don't have to do that stuff and don't have schedule things....have not had an accident (bowel) since I quit using the suppositories...about eight years.</p>	<p>I have a suprapubic in...one of the nice things about having that. Now I don't sweat unless there are problems or it backs up or it's clogged I have a leg bag emptier. Where I have a switch and it opens a valve and I drain my bag. I got to make sure that works. I drink a gallon of water a day and I fill the bag up and I got to make sure that I can empty it. [Doctors] They're trying to talk me into an ileostomy because of bladder cancer due to a suprapubic because it's always indwelling inside your bladder.... I'm happy with the way things only a 3% chance of getting bladder cancer.</p>

**Table 1: QOL Contributors/Detractors and Issues Affecting Bowel and Bladder**

Participants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA-014</b> <b>M/Hispanic</b> 62/33 yrs. Vehicular  P/C  Married Employed Spouse/SO	8.5	My military background and my medical background really, really helped me overcome all my disabilities and depression and denial...I choose quality of life over life period...If it comes to the point where I can't take care of myself I'd rather I wouldn't survive <i>[Impact of B&amp;B dysfunction on relationships]</i> I'm still the same person. <i>[B&amp;B dysfunction .on sexual relationships]</i> . doesn't make me feel great...My wife understands ...it's not an issue. But it's not like when I was 21 years old...It's important but it's not as important as it used to be <i>[goals]</i> It really hasn't impacted me.	<i>[changes in bowel routine]</i> Just my bowels pretty much from the a.m . to p.m.. Not being in control of bowel and bladder is the most important part of my body. .I can't control it but when I do have accidents, they're at home versus out in the public. Now there's a big difference there. I can't control anything but I can control where I have accidents ....I just get upset with some people that call us all disabled when they really aren't disabled in my book you know. Oh yeah, I can't walk. But as long as you can control your bowels and bladder I don't really consider someone disabled.	<i>[Secret to success]</i> I think it's because of my bladder, the way it functions. It's not like it's open all the time And when the sphincter is always closed, when I'm healthy the sphincter is always closed, both of them. When I'm not healthy if I cough or sneeze or laugh my bladder will leak and sometimes it could leak a lot or sometimes it could not leak at all or it could leak a little bit. So
<b>VA-015</b> <b>M/W</b> 67/13 yrs Vehicular T/I  Retired/ disability  Paid Caregiver	5	I work at General Motors...do a lot of dangerous stuff always lived dangerously and I'm going to die that same way. <i>[Future goals?]</i> Hope to be working on my classic cars...have a couple of vacations under my belt. <i>[Impact of B/B dysfunction-social relationships]</i> Well it has to a little bit but I mean, like I said there is no way that you could take a certain lady and be intimate with her. There's no way that it can happen. <i>[Hope to be doing 5 years down the road]</i> See I don't know,	[Bowel routine...any problems?]. No not really. It adapts, it kind of adapts to me. Whatever I'm trying to do, my bowels adapt to it... kind of adapts to me. Whatever I'm trying to do, my bowels adapt to it. t's usually once a week but the next week it might be twice a week. It's just whenever it's ready... I was going every other day and we doing that every other day. Now I go once a week like I said, if I wait until it's ready to go it takes about 15 minutes for the whole thing	<i>[Bladder dysfunction]</i> Really it didn't bother me. Not that much .It's easier for me...this is an indwelling [catheter] so...I can go out and drink two gallons of water and not have to worry about it [harder in the beginning ?] Yeah it was because I was afraid people were going to say something just because I had a leg bag on....just because it's on my leg and I couldn't bend over far enough to reach that because it hangs down to my ankles.. And I went to the hospital this week... A UTI....This is the. ...second one I've had within a month
<b>VA-016</b> <b>M/W</b> 58/28 yrs Vehicular P/C  Divorced Unemployed Alone	7.5	<i>[Impact of B/B dysfunction on relationships]</i> . not a whole lot that you can do...I can't get my arms around anybody to give them a hug and my penis doesn't get aroused. So yeah it hit me pretty hard. But on the same hand...I would rather it had done what it did do than lose my sight and my voice.. <i>[Sexuality and intimacy?]</i> Right now it doesn't bother me...there was a time that I would have liked to find somebody but I just can't. It's ....not happening. <i>[Goals?]</i> I had a good job... never went back. <i>[Sense of self]</i> . I still have my sense of humor and it's not like I've lost it	For people in wheelchairs...they always use medications like...stool softeners. I can't do that and wait. So I do rectal stim. It seems to work all the time for me... I just don't like using medicine to do it....I'm a...once a day guy. I've had a few accidents in my life but not until, God I haven't had a problem in 4 or 5 years.	[.2004 when I started with lymphedema I had one small leg and this big at my ankle. But the bladder now with the lymphedema, like I say every 40 minutes something's going to come. If not, it will just flow out on its own and it just does what it wants when it wants. I find that being with a clean catheter and my clean hand, if take one little dab and I put my finger on the head of my thing and put it in it goes in like grease lightning. You have to make sure your hands are clean, other than that I haven't had, I've had one bladder infection in 28 years.

**Table 1: QOL Contributors/Detractors and Issues Affecting Bowel and Bladder**

Participants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA-017</b> <b>M/W</b> 45/26 yrs, Vehicular P/C  Married Employed Spouse/SO	8.5	[Re Bowel/bladder]....if I had to pick...the worst part of being in a wheelchair...the loss of bladder & bowel, sex, and stairs, [most important?] probably the bowel & bladder <i>[Impact on relationships]</i> friends that I have now I met through four wheeling and camping...only two friends that I still hang out with were friends...before I was in a wheelchair <i>[Impact of B&amp;B on sexual relations]</i> ... much bigger deal before I met my wife and got married....we use injections. <i>[Future goals]</i> Still be alive. <i>[impact on sense of self]</i> I don't think it has changed who I am at all.	Like a bowel accident, maybe once a year, if that. [bowel regimen] an hour to an hour and a half. That's another sucky thing is how long it takes to do that. It's a pain in the ass....I don't know why but I get a sensation it's like a hot flash or I just start getting hot and I know that I got to go pee. Then I'll go. And if I still have that feeling then I know that I have to do bowel care. <i>[Participant describes two episodes when he had bowel accidents -very vivid accounts not feasible to include here but worthwhile to review]</i>	Have to cath... 4, 5, 6 times a day so....I have strictures in my urethra...makes it even harder to cath....biggest issues because you have accidents... I get a sensation it's like a hot flash or I just start getting hot and I know that I got to go pee....I don't get very many UTI's but if I do get one I can't hold it as much. I got to cath myself constantly [re: strictures]...had an appointment to go in with a scope and dilate, open it up and they couldn't get the scope in or some shit. [other options] Put a tube through my abdomen and drain my bladder through a tube out my stomach. I don't want that.
<b>VA-018</b> Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver	7	I do anything I want to do. I'm sure that if I wanted to do something that I could get somebody to do it with. Like if I wanted to go on a trip somewhere I'm sure I could get somebody to take me, if I wanted to. I am financially secure so I have no worries about that. My life is pretty good altogether. I mean the way I, to somebody else it might not seem, but I can't live for anybody else.		
<b>VA-025</b> <b>M/W</b> 65/26 yrs  Vehicular T/I  Married Retired/ disability  Spouse/SO	6	... both bladder and bowel do restrict me somewhat as far as social or even work is concerned....hidden part of the iceberg on that is often just like an iceberg it's greater than the unseen part is to friends and family <i>[B&amp;B dysfunction on intimate relations]</i> ...I really miss it... Even when I used things like Viagra or Cialis and right now we don't really have a sexual relationship at all/ <i>B&amp;B dysfunction on work</i> ]-see extended discussion in text] <i>[Goals 5 years]</i> ... like to be living in an easy to maintain smaller place around here. <i>[Sense of the self]</i> ...reduces your sense of self as little belittling... It's painful to deal with especially the bowel and it's just... Yeah, I'm not as happy with myself	...bowel program has changed so much throughout the years. ..I had just a terrible time in the acute care hospital. I really needed a lot of digital stimulation and all sorts of other things to get my bowels to do anything at all.... The last couple of years I switched from using the suppository to mini enema called Enemeez ... since I've done that between five and ten years, I have not experienced the bowel accidents that I have had on rare occasions with the suppositories.... Bowel day is one of the most hated days of the week. It's really dreaded. It's gone better now that I use the mini enema called Enemeez....my routine is every four days and four days seems to be working quite well...	after ...maybe ten years... I began having urinary problems and now I use a catheter every time to empty my bladder... And I began to void on my own...wonderful feeling... thought I had lost even though it did revert after a number of years to using a catheter... I'll almost always, even if I don't feel a fullness in my bladder, I'll almost always try to empty it, you know, catheter it, use a catheter and try to empty it the best I can before I go anywhere for more than an hour at least... if I'm somewhere away from home or doing errands and that I'll put up a very full bladder before grabbing a catheter tip and that from my backpack and using a public restroom or whatever. But I am set up that if I have to I can just get into the back of my van and use that..



**Table 1: QOL Contributors/Detractors and Issues Affecting Bowel and Bladder**

Par[ticipants	QOL Rating	QOL Contributors and Detractors	Bowel Practices and Issues (+ or-)	Bladder Practices and Issues (+ or-)
<b>VA-026</b> <b>M/W</b> 64/45 years Vehicular P/C  Divorced Unemployed  ??	<b>9</b>	...I wake up.. listen to talk radio, catheterize, cough up my guts from the cigarettes, hang out for a few hours, take an hour nap, wake up, putz around, wait for the crummy movie.. That's about it, <i>physical status re: QOL</i> ...ok until I broke my leg...my lifestyle changed dramatically ...don't drive anymore[ <i>B&amp;B dysfunction on intimate relations</i> ] It's what I miss the most [ <i>Life expectations</i> ] I don't think at 19 I knew what I was doing with my life [ <i>Future goals</i> ] to be alive to see my granddaughters....maybe start driving again [ <i>sense of the self</i> ]...really can't say,	[Bowel care]...really sucks...tried different ways to manage...suppositories would never move it down the only thing that works now is digital....so I only go about every three days.	[ <i>re: bladder management</i> ] not drink too much beer or water to where you extend your bladder to where it turns into an old man's bladder when you're a young man...not being able to urinate....it was important to cath to make sure it was all coming out, and probably less infections too.
<b>VA-027</b> <b>M/Hisp</b> 72/29 Fall T/I Married Retired/dis Spouse/So	<b>4.5</b>	First two, two-and a half years were real rough for me though, trying to accept being in the wheelchair....but after... more or less accepted ...didn't want to go out [of the house] I lost a lot of friends though. [ <i>what helped?</i> ] Church. [ <i>Impact of B&amp;B dysfunction on intimate relationships</i> ]... tried different things, but none of them really worked. Viagra and all of the pills and vacuum pumps, that didn't work either, [ <i>Impact on life goals</i> ] Don't know how to answer that[ <i>Future goals</i> ] About the same thing.	...but lately in the past 2-2.5 years I had a colostomy and that made a lot of difference. Well I got a pressure sore, it wasn't healing good so they were going to do surgery on it to cut all the bad skin around it and just take the skin and flap it over where the sore was and that's supposed to make it heal a lot faster. I had done that and the healing was really good So that was only suppose-ed to be temporary but I decided to keep it. It's a lot better. No more accidents. I do the bowels every other day when I have regular bowel movements. I do my Senokots the night before.	I know how long I can go. Before I had to cath and stuff like that,.

Participant	Antecedents	Mechanisms	Response Shift	Perceived QoL
	Stable or dispositional characteristics of individual, including demographics, personality, expectations, and spiritual identity.	Behavioral, cognitive, and affective processes to accommodate the changes in health status (catalyst), e.g. coping strategies, social comparisons, seeking social support, reordering goals, reframing expectations and engaging in spiritual practices.	Defined as change in the meaning of one's self-evaluation of QOL as a result of <u>changes</u> in internal standards, values and the conceptualization of QOL. (Essentially, the result of antecedents and mechanisms responding to catalyst).	Multidimensional construct incorporating physical, psychological, and social functioning. (Essentially, patient reported QoL in summary, including overall happiness/lack of happiness, wellbeing, etc.)
<b>UM-005</b>  Female White 35/19ysi Vehicular Inc Para Auto NF No caregiver	Teacher, fulltime career, hobbies are writing, exercise; health focused; injured at 16. Was hit by a car in high school. SCI level – L2-L3  <b>Response Shift: 1</b> <b>Quality of Life: 7.5</b>	I still see myself trying to recover even now. I don't think recovery ever really ends. I have a wheelchair and a walker but now can do a lot from crutches. I am afraid of falls. It is hard to walk with just a cane. It is hard when you are first injured to cath but my muscles are stronger now...	I think having SCI as a whole causes the insecurity for anyone... You don't feel as pretty, you don't feel as able, all of those things. But I've overcome those emotions... My strong point is that I don't stay in that place. I'm resilient... I attribute my healing to my faith and the Lord... I'm happy I can walk with crutches but I'm still not fulfilled.	Because I'm still not walking as good as I would like and because I still do have to catheterize, so for those two reasons. And the independence like you mentioned earlier, it's affected my social relationships. Like how independent I am feels great, but sometimes I do wish I did have more help.
<b>UM-008</b>  Female White 63/22ysi Fall Comp Para Private No caregiver	Married, worked as a commercial loan officer. Worked 21 years after her injury; co-workers very supportive. Currently retired. Owns a farm.  <b>Response Shift: 2+</b> <b>Quality of Life: 7.5</b>	...I know some people have a lot more problems than I do... Maybe I'm just fortunate I'm pretty healthy and I think the fact that I get exercise really helps to maintain my health... I just think all those things really help to maintain your health and allow you to deal with this better... I think that was important you've just sort of got to get back in the saddle and get on with your life.	...you have to get over being embarrassed about it I guess. It's just a fact of life everybody deals with... I mean you just have to sort of say look this is what I've got to do... you just mature with the whole thought of it all. It's just the way it is... Well I think you just have to come to terms with it... and realize this is the hand you've been dealt...	Well I'm, I was pretty successful in my career. You know financially I'm probably fine. I'm pretty comfortable I'm able to do some traveling and to be outside except in the winter. For the most part I've achieved a fair amount.
<b>UM-009</b>  Male White 50/28ysi Vehicular Comp Para Other No caregiver	Married. Student at UM at the time of his accident. Post-injury has been employed as a paralegal and makes custom jewelry.  <b>Response Shift: 3</b> <b>Quality of Life: 8</b>	And I suppose like anything else you just get used to things the longer they go on. You just kind of get used to having to deal with it... My wife would call that my pragmatism. She says I'm very pragmatic about everything. You know how do you do this, how do you get from A to B in the shortest amount of distance possible with the most efficient use of energy.	...it takes a little while to become accustomed to the fact that it's one more thing I have to worry about... Over time I guess I've found what my limitations are and I don't look at it as a struggle so much as just something I have to do... just notice the difference between a situation that I can have some input over and situation that have no input.. not waste my effort on things I don't have control over...	I mean I've got no real problems, you know, so I've really got nothing to complain about... Well, it's been like this for twenty-some years, so I don't waste a lot of time thinking about how things would be if it wasn't like this. This is what it is, so I guess I'm just looking at what I've got and I've got a lot.

<b>UM-010</b> Male White 35/16ysi Violence Com Para Medicare No caregiver	Not married. Injured in attempted robbery. Prior drug addictions. Associate's degree in graphic and web design. Works freelance; free to pick his own schedule. Considers himself to be lazy. <b>Response Shift: 1</b> <b>Quality of Life: 6</b>	I've pretty much gone through it all and I kind of know what to expect, you know, how to deal with different situations. But every now and then something comes up that's still surprising... And I'm still learning ways of dealing with it, you know what I mean? It still seems like each year I kind of get a little bit more understanding with how my body works...	And that's one thing I think the disability has matured me... I think if anything it's made me look at myself more realistically, you know... if I try to look at myself through rose-colored glasses then yeah, I get you know, totally like let down or something. So it makes me do a real honest evaluation of myself and what my capabilities are...	I'm not hopeless. I still see a lot of people and I'm like "I'm glad I'm not that guy or that girl," you know? I'm not stuck... I still, I've got options of what I can do with my life. And I'm still fairly healthy. I can think for myself; I can you know, I'm still fairly independent. I've still got good friends, good family; still got opportunity to make things better and do things I still want to do... I'm fairly comfortable with myself.
<b>UM-012</b> Male White 56/12ysi Vehicular Comp Tetra Auto NF Caregiver	His wife is his paid caregiver. Has other paid aids. Strong family support that helps him maintain his home. He has reframed his career as a manager into family leadership/parenting role. <b>Response Shift: 2</b> <b>Quality of Life: 5.5</b>	...it's actually allowed me to spend more time, when my boys were younger when I was first hurt, with my wife working a full time job...I'd actually spend time with the boys, teaching them how to cook dinners, to become more responsible than probably a lot of young people at their age... I'm happy to say that now I've got two young men that are self-sufficient independent.	That's probably my normal...that's who I am. I've always exercised prior to the accident... I think just that make up made a difference but at the same time I also knew when I got hurt that I needed to be able to have the strength to do things with my family... so your job's going to be to take care of yourself and continue to be as strong as possible so that this way we are able, as a family, to be able to do things... That's been my driving force	...it's always a plan, it's a schedule. It actually is a day to day schedule that many individuals that are not disabled actually can take for granted... Because I can't do everything that I once did. I remember what it's like not to necessarily live on a schedule. Yeah, you had a schedule with work. You had to be there and things like that but overall if I wanted to jump in the car and run someplace I did. And now I don't do those things.
<b>UM-013</b> Female Black 63/36ysi Vehicular Comp Tetra Other No caregiver	Single. Injured in a motor-vehicle accident. Self-reliant but wonders if she needs an assistant as she gets older. Self-reported as independent and very active in the community. <b>Response Shift: 2+</b> <b>Quality of Life: 9.5</b>	...so either get someone to help me when I'm out or I can't be out for so many hours. So that's the thing that kind of changed the quality of life is just trying to adapt to that... I've always been a person to attack any situation... I make an adjustment or if there's nothing that you can do about it you've got to just let it go... I'm really thankful that I don't have the bowel problems because a friend of mine is really going through that... I think my faith, my positive attitude and my strong will. If I didn't have that I probably wouldn't be sitting here talking to you.	I don't want to sound cocky, but I do anything and everything that I want to do. I really do.... It's just a matter of knowing where I am and what I need to do... And so I just sort of got comfortable with the fact that these things are going to happen to me... I would say the secret would be accenting the positives and trying to take care of the negatives. Don't get so caught up in all of the problems, but be aware of them and try and find solutions. And then it's just being grateful and thankful.	Because I think there's always room for improvement, but I'm pretty satisfied. I live. I don't just exist day to day. I'm busy. I'm active in my community. I wake up every morning wanting to get the day started. I love what I do. I think that I make a difference in my community and other people's lives. So those kinds of things help me to feel better about myself and it makes me think that I'm living a good life, so that's it.
<b>UM-014</b>	Married. Describes wife as devoted. C4-5 quadriplegic	I am active. I get out and do things. That's how I stay away from depression...	Don't get upset with it. Deal with it. It's who you are now. You have to... It's just	<b>Self-rated Quality of Life: 9</b>

Male White 64/41ysi Violence Comp Tetra Other Private Caregiver	injured by "horse play". Employed prior to injury as a mechanic. Has 2 children, 4 grandchildren.  <b>Response Shift: 1</b>  <b>Quality of Life: 9</b>	So I get out and go quite a lot. I don't let the chair hold me back... Don't leave things, you're responsible for...Take care of your responsibilities. Don't leave it in somebody else's hands. It won't happen.	like before. You have to get up out of bed every morning, have to do your morning routine. It's just changed a little bit... Mind over matter worked for me. So mind over matter can do anything I believe.	My belief in God... If it could be better I'd be out of the wheelchair... Go do something fun, get over it. Go find something to occupy yourself some other way. Where the wheelchair limits me so much. I just can't go do what I want to do... I was a very active person before and now I'm not.
<b>UM-017</b> Male White 43/24ysi Sports Comp Tetra Self-pay Caregiver	Unmarried. Quadriplegic C 5-6, injured in diving accident. Has supportive parents and sister who act as his caregivers.  <b>Response Shift: 2</b>  <b>Quality of Life: 10</b>	So I've always struggled. So being in that wheelchair was just a different struggle... So started realizing and understanding how much it does take. It is a job and I pay very close attention to it, and it's the only way, if I didn't I wouldn't be happy. I would be sad. I wouldn't be as happy if I didn't pay the close attention.	I've learned a whole bunch. I really have, and I can really help others in this position.... you start looking through a different window. It's not what it was... and we're going to be in misery for a long time, move ahead. Did that happen? No. Took me two years. I beat my head off shit for two years. Didn't happen overnight.	I'm very, very happy. I'm full of joy. I have everything that I could ever dream of before my accident, I have it right now. I have a beautiful girl that loves me. I have a home that's beautiful. I have friends and loved ones that are there for me. It's just so many good things in my life... Good things are happening.
<b>UM-018</b> Male Hispanic 30/10ysi Sports Incom Tetra Medicare Caregiver	Married to someone he dated prior to injury but was not dating at the time of injury. C5-C6 injury. Finishing studies at Alma College  <b>Response Shift: 1</b>  <b>Quality of Life: 7</b>	Yeah, it's something my mom taught me to do, is to be my own advocate. And I kind of just followed her example while I was in the hospital. You know, I saw how she took care of business dealing with the system... so I try to adopt the fake it until you make it philosophy and that's actually been quite successful or at least it gets me up and doing things.	I was just kind of taking it a day at a time during the summer before my injury. Once the injury happened it was like okay, I still have to take things a day at a time, but I've got fewer paths available to me to that bright shining future that all of us are striving for. Now I really don't see any path to it at all, so I just kind of exist one day at a time.	It's just shy of so-so okay, but it's definitely not the worst it could be. You know I still live in the first world and that's nice and I have first world problems... It happens when the things that I'm doing turn from interesting and fun to boring and repetitive, so there's that.
<b>UM-020</b> Female White 52/17ysi Vehicular Comp Tetra Other Caregiver	Married when injury occurred now divorced. Does not attribute end of marriage to SCI. PhD in Rehab Counseling.  <b>Response Shift: 3</b>  <b>Quality of Life: 9.5</b>	...it's a part of being human and that it didn't kill you and maybe those kinds of things... In the beginning I would say that it had a pretty significant impact on me. It did. It was hard, it was embarrassing, it was a struggle... Just the drudgery of having to do it and some of the embarrassment of people knowing.	It's all about adjustment... it's not something that I'm at all embarrassed about or ashamed about. It's just part of the process of having a spinal cord injury... I'm happy with my life. I'm not sitting in the chair waiting for the cure... I'm very, very resilient and I think that that's what I can attribute to being where I'm at.	I'm totally empowered; I love what I do... I've achieved everything that I wanted to achieve in my life and more. I've actually exceeded my expectations of what I thought my life would be. And to be honest with you, had I not had the spinal cord injury I don't know that I would be saying that.
<b>UM-021</b> Female White	Retired police officer. Injured via abscess but is slowly regaining mobility and may	I marveled at the ones that would get up, get dressed and make it to work every morning over there at Shepherd's... And I	Initially, it did, I guess, a lot more just because the bowel, especially. I was just...it was just so hard. Now, I can just	...is there some place or something else I could be doing to enhance my situation to make it better, to make me stronger, give

55/1ysi Medical Incomp Para Other priv Caregiver	still walk one day. Married; husband supportive.  <b>Response Shift: 1</b> <b>Quality of Life: 9.5</b>	could get moving a lot quicker than I do too. I just don't have to... I never did the "Oh, woes me," but I did think really, I said, "For me, as much as I like to walk and do things like that," and then I thought, "Well, would I have rather been blinded?"... you take what you can get.	get up and get going... My life's goal is to be happy and healthy and I am. So this is just different... I could have gotten shot and killed 20 years ago... things happen to everybody. We just kind of lived a charmed life and this happened and you have to deal with it.	me any other chances so I can be self-sufficient and stay that way a long time?... You just have to put yourself out there and go do it. My goals aren't changing really... My sense of self, I'm still very confident... And I've been lucky I've been able to learn to do it myself.
<b>UM-023</b>  Male White 57/1ysi Fall Incomp Para Medicaid No caregiver	Unmarried. 3 daughters. Has lived with his mother since his father died prior to the injury... he fell out of a tree-stand, T-12 injury.  <b>Response Shift: 1</b> <b>Quality of Life: 5.5</b>	Well, when you hear stuff like that, even though I was in bad shape at least I was walking... when you get severely injured if you don't want to die there's a lot of things you say to yourself you're going to have to do if you want to live. It just comes down to that plain and simple – if you want to live this is what you're going to have to do.	I never did [go out] even before my accident. I didn't go too many places... But if my bowels and my bladder don't straighten out and this is what I have to continue doing I'll do it. Like I say, there are certain things you're going to have to do different in your life than what you did before.	You look at some people that maybe have got it better than you and they've got this big old freaking mansion... But if you look on the other end of the spectrum there are probably some people that aren't as well off as what you are... You're always going to be able to find somebody that's better off than you are and people that are probably worse off than you are.
<b>UM-030</b>  Female White 45/1ysi Fall Incomp Para Medicaid Caregiver	Married, NH. Injury occurred at home with a fall down the stairs, breaking C6 to C7 and T1 has been damaged. HIV Positive.  <b>Response Shift: 1</b> <b>Quality of Life: 5</b>	I think that kind of made me feel like "Oh my God, why did this happen to me?"... but there was people that was worse off than me... Okay, I should be just thankful that I'm here and I can move more parts of my body than my legs... it's like being a baby all over again, learning how... As an adult you have to learn it all over again.	Me, I just look at it as part of the spinal cord injury and it's just something I have to deal with and figure out what I can do to fix it...so I feel like I've been given that second chance. I do. And somebody's told me I need to change a little bit or something. It's hit me hard. But I'm going to do what I can do, and I'm happy.	Like in the middle. I'm all right. I'm happy with it, but I want more. I wanted to -- I want it to be more happy... Being able to get out more and go see people, get my mind off of things. Being able to go out and watch birds, watch nature stuff. Just because I'm in a wheelchair doesn't mean I can't still do those things.
<b>UM-038</b>  Female White 36/1ysi Vehicular Comp Para Auto NF Caregiver	Fiancé caregiver, together prior to injury. T7 injury, has use of hands and arms. Has bowel sensation.  <b>Response Shift: 1</b> <b>Quality of Life: 5</b>	You have to rely on somebody to get you, you have to take pills to go poop... Well like I said I do what I can do and if I can't do it I figure a way out to do it... It's very hard for my family that I guess, that's something that should be addressed with the patient.	Basically I'm starting over... You know just because I'm paralyzed there just a new way of doing things. If I had my legs I wouldn't have this problem. The doctors need to work on some stuff and give me my legs back... I dealt with my injury and it had to be done so I deal with it.	Because it's not bad and it's not good. You make it out to what it is... Walking, being able to drive, ride a bike, doing things I used to do. So that's where I have to rely on people to take care of me. I don't like that... Just getting used to the lifestyle... Well my dream got taken away and my husband's did, all of them.
<b>UM-039</b>  Male White 42/1ysi	Mountain bike accident. College football. Military for 5 years. Divorced. Obese but trying to lose weight. Has a 7 year old son motivating him.	I immediately went into prayer mode... Please wash my sins away because I don't want to hell... It's been a long road though. It plays on you emotionally and mentally when you can't control your	I went for 41 years thinking I was invincible then all of a sudden very humbling... It definitely changed who I am... I don't judge people too quickly because I don't look the same... During the	Well, because before I got hurt I would probably have rated myself at eight... You know, just because I still wasn't as physically fit as I could have been, you know. So, you know, I'd say a six because

Sports Incomp Para Other priv No caregiver <b>VETERAN</b>	Can walk.  <b>Response Shift: 1</b>  <b>Quality of Life: 6</b>	bowel... I felt less of a man... But it got a lot better... I went through some rigorous training. Just some mental toughness... that's the whole military style	first few months of my injury, you know, depression, I was eating garbage... now I am at least eating well... I learned how to live with it...	I'm more than half better than when I first started, when I first got home from the hospital, you know, so, if it's more than half, I'm going to have to say about 60%.
<b>UM-040</b>  Male White 61/1ysi Fall Comp Para Other Priv Caregiver	Married, adult children. Engineer for car seats. Currently has short-term disability. Injured less than 6 mos. Has some feelings in legs. Resides at rehab facility  <b>Response Shift: 1</b>  <b>Quality of Life: 7</b>	...you can sit and feel sorry for yourself and dwell on it or you can take it day-by-day that you're waking up and you know you're here... I get up every morning and just thank God that I got another day... little things that I have to deal with aren't that big when you look at some other people... I could have been killed pretty easy so I'm just thankful to be here...	...it hasn't beat me up at all; hasn't changed me a bit. My nurses come in and they deal with it every day and I have to deal with it... you just take care of business and get on with it... you're looking at 10 months for all that to heal up... Then you're gonna have some rehab on top of that. Just grin and bear it and work hard.	I'm totally comfortable here at this facility. All the people are very good. They do their services to the people that are here pretty much on timely schedules and within an acceptable range of... as far as doing a complete job and on time. The facility here is just beautiful... It's been really good... Seven actually is probably a conservative number but I...
<b>UM-041</b>  Male White 60/1ysi Medical Comp Para Other priv No caregiver <b>VETERAN</b>	Retired. Divorced. Lives alone. Had an aneurysm; paralyzed during the surgery. Has 3 supportive children. Has grandchildren.  <b>Response Shift: 0</b>  <b>Quality of Life: 7</b>	This is something that you have to learn how to do by yourself. There's not going to be anybody there to help... Well, I think that I was used to living alone. I think that that probably made this a little bit easier... I know things could be a lot worse... So it doesn't take a whole lot to see that things could be worse...	The whole thing still at this point is kind of a learning thing. And still hoping like heck that everything eventually gets better.... And it's going to take a while before I quit hoping that... I think like you said humans just adapt to the situation you're in... Everything you did was a chore. Everything. But you figure ways out.	...life is kind of blah right now. I've watched more TV since I've been out of the hospital than I've seen in years... if I don't get my legs back, it's just awful hard to see how things can get a whole lot better than where they're at right now. Which I know they can... I think that it [bladder and bowel] definitely messes up your quality of life.
<b>UM-042</b>  Male White 55/1ysi Fall Incomp Para Medicare No caregiver	Married. Was separated at the time of injury. C5-C6 injury. Walks with a cane  <b>Response Shift: 1</b>  <b>Quality of Life: 2</b>	Well, yeah, my life's way more difficult than just this injury; but it's like the icing on the cake. It just – everything got taken from me and then now my health. It's just unbelievable. I lost everything... like fuck, you're counting every penny and it's – and now I'm like one of them and I don't want to be one of them...	Now we're out here. So I have no idea of where I would be if I – I can't even think that far. I used to fear the future even when I had everything in the world going for me... now I don't even think about it... to think that I'm going to live the rest of my life like this is not good... but in totality, you know, it's still minor thing.	I always look at – my friend tells me... things could even get worse and as a matter of fact they have over time. I don't know because mine is probably relatively minor maybe compared to some people... Finding something I truly love to do which I've never found... I don't even like to think about the next day.
<b>UM-043</b>  Male White 33/1ysi Sports Incomp	Recently divorced prior to injury. Injured during a workout using a pull-up bar. Now living with parents.  <b>Response Shift: 2</b>	I just kind of roll with the punches... And then after a certain point, then it just becomes kind of normal... I guess I dealt with it pretty well, but I could see how some people wouldn't be able to deal with it too well... Everyone says this is a	It is what it is. You do lose all that modesty of just being embarrassed about it because it is just a part of your life and it's going to be a part of your life for the rest of your life. You can't hide something like that... I guess it really hasn't changed my	...actually having people there by your side; that definitely helps. I don't know why I took it so well. I'm not really too sure. Like I said, I was ready for a change anyway, and maybe this is just the kick in the ass that I needed. I don't know... It's a

Tetra Other Priv Caregiver	<b>Quality of Life: 6.5</b>	permanent deal... It's kind of up to you to try to figure out how to make it better... That's really the biggest change is having to rely on people... realizing that was one of the hardest things.	goals; it's just made them more important. All my goals are still the same... Yeah, it has motivated me a lot more to be a better person.	big change, but I don't think it really changed my quality of life too much... once you get everything in control and you start understanding everything, then it becomes less of an issue.
<b>UM-044</b>  Female White 27/1ysi Medical Incomp Tetra Other priv Caregiver	Unmarried. Dating someone since prior to injury. Currently living with parents. Diabetes ketoacidosis, which then led to a stroke to the spinal cord.  <b>Response Shift: 1+</b>  <b>Quality of Life: 7.5</b>	I'm still hoping that I can walk again and I'm you know, I'm very determined. I'm very strong-willed and sometimes stubborn so I'm not going to give up... Things happen for a reason. For some reason God wanted me to go through this process. I mean maybe I'll learn something... I mean me bitching about it and me being sad is not going to change the outcome.	But I mean everything just changes. You look at everything differently. Just your outcome on life you know, you start to appreciate things better... I used to run all the time which I don't run anymore, but I've picked up new [hobbies] that I haven't done before. Like I started painting at therapy because it was working on my hands. So I mean I picked up painting which I never did before.	I try to see the positive in anything and I you know, my hands are moving more now. I have more – my vocal cords, like everything's working. So if I keep telling myself I'm really good, maybe one day I'll believe it you know, sort of thing. So I mean I'm not the best but I'm not the worst...
<b>VA-002</b>  Male White 45/20ysi Vehicular Incom Tetra VA Caregiver	Lives with his wife. Currently employed. Injured in motorcycle accident. Military background (Marines) but no mention otherwise. Injury inspired him to college.  <b>Response Shift: 2+</b>  <b>Quality of Life: 8.5</b>	...it's just a matter of timing things out... It's a procedure to get in there, do the catheter, and get out, you know can't be rushed... if everyone is going out bar hopping or clubbing or whatever, I don't go because I'm not going to be out running around. I need to be able to find a restroom... I'm a much more empathetic and understanding person than I ever used to be.	I still write left-handed, I still put pants one leg at a time, but not much that didn't change. I still like doing the same things I just have to do them differently... they used to have a shrink come in and talk to us... she kept telling me, you're going to go through a depressed phase. About three months in she goes, you know I don't think you're going to go through it... this is what I have to live with and I'm too young to sit here and rot.	Because for the most part I'm pretty happy with the way my life is.... I have a good job, I have a good wife, my kids are healthy, fairly intelligent, not killing each other yet. So yeah, for the most part life's pretty darn good. Could it be better? Sure, I could wake up tomorrow and have full bowel and bladder control. Not going to happen... Things could be always be better and always be worse... my spinal cord injury altogether changed my life goals.
<b>VA-003</b>  Male White 35/13ysi Vehicular Comp Tetra VA Caregiver	Injured in a car accident. Married, one child. Seemed guarded in interview. Served in Air Force; injured while enlisted.  <b>Response Shift: 1</b>  <b>Quality of Life: 8.5</b>	You go from being self-sufficient and doing what needs to be done to depending on people around you...I've been pretty fortunate from baseline of injury to now... As I talked to urology more and more, I said why don't we make it a constant drain and be done with it? So that's what we ended up doing... But that's me, everybody's different.	I have a system now... It hasn't changed me. I mean it is what it is... You have to have the drive to do the things that you want to do. If you've got no drive, you're just not going to make it. You'll become that recluse, that person that hides from their problems... I mean just that drive to never give up. That's just the way I've been. If there's something you want to do, there's a way to do it.	You know, there's things that could always be better. But they could always be a lot worse... The time I get to spend with my son. There was a lot of years that I wasn't around him.

<b>VA-004</b> Male White 43/10ysi Sports Comp Para VA No caregiver	ATV accident. Had bladder augmentation surgery 4 years go and likes the results. Divorced and has a daughter. Was in the Army 4 years after high school <b>Response Shift: 2</b> <b>Quality of Life: 9</b>	About 6 years ago... I came to the point where I didn't care (about bowel accidents). If it happens it happens... And I guess try and become more in tune with your body... Basically I don't want to get in another relationship... I'm content with being able to do whatever I want, whenever I want, however I want... I'm pretty content with the way things are right now.	Just getting on with life basically. Not letting that aspect of it (bowel and bladder) control my life... I am not going to let it control my life. I'm going to live my life. If I have an accident it happens. That's my attitude now... At first, yeah it did affect me. But now, I know it sounds weird, but I basically don't even consider myself in a wheelchair now... Not to let it control your life.	Because if I said 10 then there's no room for improvement... My daughter, the dog definitely helps improve my quality of life. I don't know. That's kind of a tough question. I've never really thought about it.... My daughter, the dog definitely helps improve my quality of life.
<b>VA-006</b> Male White 57/36ysi Vehicular Comp Para VA No caregiver	Married and divorced twice post-injury. Injured in a motorcycle accident. T-5 injury. He was a radio technician in the air force. He is currently retired. <b>Response Shift: 2</b> <b>Quality of Life: 7.5</b>	...there was a huge ward of all these other spinal cord injured people, and most of them were worse than me. So I started thinking, I could definitely be a lot worse off... I've never been one to give up... I don't want to give up on it, I want to get it done... (family) say I'm the strongest one... maybe part of that is I don't want to let them down.	Like I usually tell people, you have to play the hand you're dealt... I guess I feel stronger in a way. You know just having to deal with a lot more than I've ever had to deal with, or that the average person has to deal with as far as that kind of stuff... it's an independence thing. You want to be able to prove that you're still able to get along on your own... to enjoy life.	Because it's certainly not a 10, but it's pretty good. There's things I got to deal with but that's just the hand of cards I'm dealt and I have to make the most of it. I'd like some things to be different, but I'm glad that a lot of things are the way they are too, you know... It's a significant change in lifestyle that you have to make allowances for...
<b>VA-008</b> Male Black 48/26ysi Vehicular Comp Para VA No caregiver	Married for 22 yrs. T5-6 Spinal cord injury. His caregiver is his spouse. Has 2 children. Is a professional photographer. <b>Response Shift: 2</b> <b>Quality of Life: 10</b>	I actually picked up my wheelchair and I threw it across the room. I sat in bed and I actually cried. I was like why? Why is this? Why is this happening to me? At that point, the tears turned to laughter... I just had a moment with God, I just said you know what, I'm tired of this. I just can't take this anymore. I heard a voice that said don't worry about it, I got you.	...I'm not embarrassed about that anymore... Once I learned my body and accepted that this is my life, that's how I dealt with it... they see me as the normal dad. They don't know anything different. I still cook. I still got to wash the floor... I'm at the basketball games. I'm at the football games... They don't look at me any different because I'm in a wheelchair.	I wouldn't change anything. I got two wonderful boys. I've been married over 20 years. My life is perfect. People say that, like I said, being in the chair is not the hard part. Once I conquered dealing with the bladder and the bowel, once I conquered that, I never looked back.
<b>VA-011</b> Male Black 48/16ysi Vehicular Incom Tetra Auto NF Caregiver	Married with 3 adult children and two children in high school. C5-C6 injury, has some sensation and can walk a little. <b>Response shift: 2</b> <b>Quality of Life: 9.5</b>	...early on it all is quite overwhelming... So there's a lot of exploring your mind and wondering a lot... Because there's so much to take in, don't try to figure it all out right now... I was raised in a Baptist church. And to tell you, it was just a spiritual journey for me, it really was... Having a strong intact family, network has been a source of comfort for me.	I realized that my situation could have been much worse and I'm thankful for what I have. And really coming to a place psychologically, this was the problem and the key, to understanding that being in wheelchair does not make me less of a man or a human being. Once I was able to deal with that... I was in a good place and I was able to move forward with my life...	Just the place I am now, I'm happy, I'm fairly healthy, my family is in a good place. I'm in a place where I can give back. I can give to others and make a difference in other people's lives which is something I've always wanted to do. So I'm there now. So I think to me that, for me that quantifies success.



<b>VA-012</b> Male White 56/27ysi Vehicular Comp Para Other Priv No caregiver	Unmarried. Lives alone. T5 injury. Car flipped over on his vehicle. Employed as an executive director of a spinal cord injury organization.  <b>Response Shift: 2</b>  <b>Quality of Life: 9</b>	... my coping skills and my attitude when I look back on it, I've always been a positive person... And so the adjustment period for me wasn't as difficult as it was for other patients... I go and see people in the hospitals that are in far worse situations... I took a situation that I wouldn't even wish on my worst enemy and made it work... So I controlled the injury, I didn't let it control me.	Well I was devastated. At first I didn't believe it... then it hit home for the first time for me that this was the way it was going to be... you move on and your goal is to try to do what is necessary so you can eventually go home and get on with your life again... I've learned a lot about myself... I was given a hand and I was able to make it work, everything work for me.	The reason I didn't pick 10 is it's not perfect and a lot of it revolves around the bowel issues. It's just as I said, as I've gotten older it starts to control more of what you do, in terms of you controlling it. [Regarding auto coverage] So either way we are blessed. We get the supports necessary to make it work. The ones that fall through the cracks are the ones that have a difficult challenge ahead of them.
<b>VA-013</b> Male White 56/37ysi Fall Incom Tetra VA Caregiver	Injured by falling. Has had a consistent caregiver for 15 years that turned into a romantic relationship 5-6 years ago. Retired computer programmer  <b>Response Shift: 1</b>  <b>Quality of Life: 8.5</b>	I go to church every now and then. Volunteering, I guess I volunteer, but I don't volunteer on organizations or things like that. Somebody may ask me to help them out, I guess that's volunteering... But you know things like that, just an everyday thing... Being young I guess because the younger you are the more accepting you are.	It wasn't so traumatic. I don't think I went through a lot of traumatic experiences learning as some of the other people did... if it's gotta be what it's gotta be, let's get on with it... that's a part of life. You have the same things that I do except that you can do it a lot easier than I can...I accepted it. I wanted to look forward and do what I had to do to get on with life I guess.	Why? That number, I don't know. It could be a little better. I could be in Florida, not in the cold. I could be out traveling. But overall, every day I say a prayer and I thank God for the life I have, for everything I have, for my family and my friends. So I'm pretty, I'm thankful because I'm happy with what I got despite my injury. I think I got it pretty good.
<b>VA-014</b> Male Hispanic 62/33ysi Vehicular Comp Para Other Priv No caregiver	Married. T11-L1 injury. Hit by a truck while walking. Was a Navy corpsman taking care of spinal cord injuries. Employed full-time at GM  <b>Response Shift: 2</b>  <b>Quality of Life: 8.5</b>	My military background and my medical background really, really helped me overcome all my disabilities and depression and denial... A lot of people take years and years to get over that... you're going to have to pick up your pants and put your boots on and start over. Because once you hit rock bottom there's only one place to go.	If it comes to the point where I can't take care of myself I'd rather that I wouldn't survive... Why me?... I knew there was never an answer to it so I just moved on. It didn't take me long... It's just going to determine how I move on down the road. I knew there was nothing I could do to change it... it was a done deal and I had to make the best of it.	Because I have a job and I'm healthy and I make a lot of money... Free time and to do leisure activities... I'm looking out for me. I want to get myself back in shape because I may not be able to walk around but I'm healthier than most people out there... I'm in really good shape in that respect, you know. So I want to take care of myself and go out and I love physical exercise.
<b>VA-015</b> Male White 67/13ysi Vehicular Incom Tetra VA Caregiver	Unmarried. Three adult sons. Ex-wife acted as caregiver briefly after his girlfriend died in a motorcycle accident. Has some mobility.  <b>Response Shift: 1</b>  <b>Quality of Life: 5</b>	And the good Lord said to me, "Now I've got a good handle on you. I don't have to worry about where you're going because I know where you're at now all the time." So this is the Lord's way of saying... it's slow down time... Regardless how bad you are... there's always somebody around the corner somewhere that's worse than you are.	I don't think a whole lot. I mean I still have my sense of humor and it's not like I've lost it... it hit me pretty hard. But on the same hand if you turn it over... If I had lost my sight and boys, I would be in a corner some place with a rope around my neck... The good Lord knew what he was doing. He hurt me just enough to make me slow down...	Well it balances because you've got that balance. You've got to have the feeling that you can still do what you want to do but on the other hand you've still got that little bit of pressure pushing down on you just saying just chill out because you're right at all you can do. There's no need to get anxious and think that you can do something that you can't do.

<b>VA-016</b> Male White 58/28ysi Vehicular Comp Para VA No caregiver	Injured in a motorcycle accident. Suffers from lymphedema. Self-employed as a "dog behavioralist".  <b>Response Shift: 0</b>  <b>Quality of Life: 7.5</b>	I'm not asking God to walk, bowels and bladder would be nice. They say this is incurable... I can't believe the creator of everything made something incurable... let's put it this way, if I ever got down, if I ever got blue, or if I ever gave up it would probably crush my family... I ever quit trying, it would probably kill them....	You can't stop me. When you become paralyzed you either got to get into life or not... But yeah, my goal is to do dogs. And I don't do a lot of them. I just, over the years I've done hundreds... Well I was raised rough and tough on a farm. I was raised around tough men and tough everything... And I've been fine ever since.	...I don't ever give up. I don't ever surrender. I never give in no matter how bad it feels... But again, that's just everything combined into itself so it's just something you have to live with so I can never be so-so. I've never been in the middle. I've always been to the better, always been to the better.
<b>VA-017</b> Male White 45/26ysi Vehicular Comp Para VA No caregiver	Hurt while in the Marines. Aircraft mechanic. Married well after his accident and they adopted two boys.  <b>Response Shift: 1</b>  <b>Quality of Life: 8.5</b>	I just needed to prove to myself and everybody else that I was independent... there was a lot of quadriplegics [on his ward] that couldn't take care of themselves at all... I've always been like that. There's no sense in getting upset over something that you have no control over. I think one reason that I accept things so well is because my accident was nobody's fault but my own.	Just to see how far I could push everything. It made me feel more alive. But that's why I never thought I'd live past the age 40. But now, I'm married with kids and everything has changed... I have accepted who I am in a wheelchair... I don't really think about what I've lost. I just think about what I can do, what I can still do and what I still want to do and how I can accomplish that.	Well because things could be better. I could have more money. I could have a better job. Things could be a lot worse, but I think things could only be a little bit better. Things are pretty good.
<b>VA-018</b> Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver	Was a sergeant in the Army. His sister is his main caregiver. No relationships or friendships other than family.  <b>Response Shift: 0</b>  <b>Quality of Life: 7</b>	[Regarding bowel program] So if that's what's got to be done, then it's got to be done... You have no control over your own life... you always have to depend on somebody else do something for you... It's just something that you have to deal with, so you do. You could die but then you'd say, damn you're going to miss the soap opera tomorrow. [Military] You had a sense of accomplishment.	It doesn't make me feel any worthless or worth more, so it just is what it is. When you've lived with it for this long, you just say, "Shit happens, sometimes more than not." But that's the way it is. When people wear the t-shirts "Shit happens", that's literally my life... it's a hassle and it wears on your nerves and sometimes it can be embarrassing. That's just something you learn to deal with...	I do anything I want to do. I'm sure that if I wanted to do something that I could get somebody to do it with. Like if I wanted to go on a trip somewhere I'm sure I could get somebody to take me, if I wanted to. I am financially secure so I have no worries about that. My life is pretty good altogether. I mean the way I, to somebody else it might not seem, but I can't live for anybody else.
<b>VA-025</b> Male White 65/26ysi Vehicular Incomp Tetra Auto NF No caregiver	Injured in an auto accident. Married to the same woman throughout. 2 children. Medic in the Air Force.  <b>Response Shift: 1</b>  <b>Quality of Life: 6</b>	... his injury being so complete he really needed care 24 hours a day, seven days a... I had such a good recovery where he had really rough recovery and needed a lot of help... I wasn't an A Type personality. I wasn't the real aggressive go-getter, got to win every game type of person. I was more the type of personality that could go with the flow...	On many of the days, especially the days with a bowel movement I will say I'm more depressed and more ornery...in a way it reduces your sense of self as little belittling. You just feel that it takes up so much time. It's ugly to deal with. It's painful to deal with especially the bowel and it's just... it just takes a lot out of me... I just don't feel as good about myself.	I do feel down. Quite often I do get depressed about the situation. I feel following spinal cord injury I'm so limited as to... I'm much more limited as to what my options are... It's just not a great shiny outlook... I don't like the idea of someone having to take care of me on a regular basis and yet I know if I live long enough and chances are that will happen.

<b>VA-026</b> Male White 64/45ysi Vehicular Comp Para VA No caregiver	Injured in an auto accident while on active duty. Divorced. Never worked. Step father to 3 sons. Been living alone for 25 years. <b>Response Shift: 1</b> <b>Quality of Life: 9</b>	It was pretty devastating, but I had no choice and I had to adapt... I just put everything out of my mind and got into drugs the first couple years... Accept it and move on or take the path that leads to no good... When I was paralyzed I was independent, everything was going ok... But it's to the point where it doesn't really even matter anymore.	I calmed down a whole lot actually a long time ago... Just growing up, I guess... You can't sit around and say woe is me. You have to wipe your butt and get out of the house... Well I really had no idea. I just accepted my situation and that was that. It was all out of my control and there was nothing I could say or do to make any difference. It's either hang in there or die.	Well it's because I don't care anymore. I give up. I'm not depressed. I accept my life, that's all... I know how it is and how it has been and that's the way it is... So I don't think about it or worry about it... Well, it sucks. It's a struggle, but it's ok... Yeah I just live with it. I stick to the plan... Yeah and for my life. Get your little butt up and try to be happy...
<b>VA-027</b> Male Hispanic 72/29ysi Fall Incomp Tetra Medicare Caregiver	Work for Ford and as a landscaper. Injured falling down stairs. Married. His wife helps with his care, since he cannot cath himself. Has other paid aids. <b>Response Shift: 1</b> <b>Quality of Life: 4.5</b>	First two, two-and a half years were real rough for me though, trying to accept being in the wheelchair... it took quite a while, but after that I more or less accepted that I was going to be like this... a lot of people couldn't accept it either, they were kind of shocked. They didn't know how to go about it, trying to talk to me about it.	Well I figured that was the, when I was born, that was the route that was already made for me. And this is the way I have to stay like this and there was nothing I could change. You either accept it or deny it and then just be miserable... How do I deal with it? More or less I think you try to ignore it I guess... I think it has me changed some...	Because everything else, we can go any other place and it would be more or less the same but it also takes money to go out. Like I said, we always used to go and now you have to watch it like how long you can go... Well, being with my wife. She's stuck it out with me through all of this even though she gets grumpy every now and then.
<b>VA-029</b> Male White 55/17ysi Violence Comp Para VA No caregiver	Parents/wife all died over a five year period, leading him to substance abuse to cope. Has a hard time maintaining employment due to bowel. <b>Response Shift: 2</b> <b>Quality of Life: 6</b>	Well I was lucky because I had previous medical experience. I knew what was ahead of me... Knowing it and accepting it are two different things, it took me a while to come to grips with it... I don't know what it was inside people that make some people give up and some people fight... I was adamant about that, like I'm not going to let this change me or change who I am, define who I am.	...the things everybody wants in life, love, family, that's over. That's not going to happen for me... So I've just accepted my lot... And knowing it in your head is confidence, 90% of it is confidence... It's hard to accept, I just didn't want to live at first... But after a few weeks in the hospital, once I got up and around... and seeing that life goes on... I'm not going to let that guy take my life away.	At this stage, at age 55 I don't have much time left on the planet. I'm not going to be starting a family. I'm not going to be, so those things are gone, but that doesn't mean that there's not still something to live for. Yeah, I've missed out on that and I've come to grips with that. I'm ok with that. For whatever reason, that's the way it is.
<b>VA-030</b> Male White 64/21ysi Medical Incomp Tetra Other Priv No caregiver	Works as a hospice chaplain. Seems very fixated on his bladder and bowel issues. Holds himself to his old standards. Naval Reserves. <b>Response Shift: 0</b> <b>Quality of Life: 8</b>	...I'm pretty open. I'm not afraid to tell people if they ask. I'm not ashamed of it. Smelling like urine can sometimes be disheartening, especially when I'm visiting people because I'm a hospice chaplain... My wife wants no part of it... My wife is kind of a germaphobe... I don't want or need her to be... Other than that, nobody really knows a whole lot...	No, I try to keep it as private as I can. I'm not ashamed of it or anything, but I try to be as private about it as I can... Well I have the job I wanted, doing what I want to do, as long as I can keep well... I'm pretty good with myself. I'm not afraid of it... I'm pretty well balanced out and God has given me the grace to do what I do...	Because I like what I'm doing, I like my life. Everything would be great if I didn't have bladder and bowel problems. But I'm not going to let that affect what I do and who I am... My work, getting in to visiting people who are at the end of their life and being a part of who they are and what they do... God gives you the grace to do it, to do what he asks you to do...

<b>VA-033</b> Male White 69/27ysi Fall Comp Para Medicare Caregiver	Highly supportive wife and strong military background. Injured when falling out of a tree while hunting. Has 2 daughters, 12 grandkids.  <b>Response Shift: 2</b>  <b>Quality of Life: 7</b>	I had to learn to do everything for myself. My wife helped me a little bit, but as little as possible, so I could become more dependent on myself than her. We made the adjustment and it has worked... I've seen a lot of guys that had accidents, diving accidents or something, where life, they were right on top... Just the fact that I love the Lord and I think he helps me through a lot... you get a strength from that where you think things are going to be better someday.	I guess because I want to feel as much of a man as I can. I realized there's things that I can't do now that I used to do. But I never let that get me down... I don't think it has changed me as a person. I'm the same person I always was... See I don't get up in the morning thinking oh God, I'm paralyzed. Because if I do think about being paralyzed it can get to me. But I get up in the morning thinking well what am I going to do today?... I feel like my life is still complete to a degree.	...it's the fact that I can go through and say 8 or 9 but I won't say 10 because it's senseless to say that you're at 10 when you're in a wheelchair. Well I picked a 7 because it's not just so-so, so I picked the one right after it... Well I could have went for an 8 or 9 but the fact of the bladder having to get out and make sure that you have this and that to do the bladder and your urine and everything like that.
<b>VA-035</b> Male Black 62/28ysi Violence Comp Para VA Caregiver	Unemployed. Paralyzed via gunshot. Has 3 sons and 4 grandsons. Credits the VA with taking very good care of him:  <b>Response Shift: 2+</b>  <b>Quality of Life: 10</b>	I didn't know anything really about being paralyzed when I first got shot but I had a friend of mine that was paralyzed. So he was teaching me... I know what I have to do to survive and I'm not the only person, I wasn't the first one and I'm not going to be the last one... When I got shot, I had a good attitude... My survival skills because I had to learn that when... I was in the infantry... I believe in Jesus Christ... and positive people around me that are helping me... I'm independent.	I'm adjusted to this. I've accepted the condition I'm in because it could be a lot worse... some guys in wheelchairs they confine themselves in, they confine themselves away from people.... But I'm not that type... I still knew who I was in the wheelchair. It was not like I'm living in it, I'm just using it. I don't sleep in it... I guess they see me in the wheelchair and they just see a glow in me. They just see me with a smile on my face...	Because I feel that way and I'm living that way... Just looking at TV, looking out the window, minding my own business, minding my P's and Q's... That I'm alive and still in my right mind... It is a good thing. A lot of people didn't wake up this morning; they didn't wake up in their right mind either.

## Response Shift-Quality of Life Thematic Analysis

Response Shift Theme	Description of theme	Connection to QOL	Subjects with this theme
Behavior-driven response shift	Shows particular determination to take an active role in redefining social roles, finding and maintaining employment, processing through the injury and actively building a quality of life for themselves; includes reconceptualization of QOL and a shift in internal standards. Redefines self but also adds new behaviors.  Includes: change in behaviors, reconceptualizes roles in life, positive affect, shift in standards	Accepting can no longer do all the same tasks as before; cites room for improvement but overall happy with life circumstances. Empowerment, efficacy over decisions, seeing the positive, and cites the “good” things about life. Ability to reconceptualize their lives and take action is either caused by or results in higher QOL ratings – some cite support leading to new behaviors and therefore improved QOL, others cite their adaptation being fueled by a good QOL thereby enabling their response shift. Bladder and bowel are rarely cited at all.	UM-012; UM-013; UM-014; UM-020; UM-040; UM-044; VA-002; VA-004; VA-012  Total: 9; Vets: 3; New: 2; Female: 3 Average QOL: 8.28 Average RS: 1.67
Awareness-driven response shift	Shows particular focus on reconceptualization of self, new sense of who the person is following their injury, but little to no shift in behaviors beyond what is necessary to live with an SCI and manage bladder and bowel. Talk of being a better person, growing up; changing internal standards and values regarding self.  Includes: general positive affect, shift in standards, self-improvement	Discuss some achievements in the past, no “real” problems, and not being hopeless. Cites strong family support or making comparisons that their lives could be worse like others they know. Optimistic that their lives are better than average. Talk is more around what they have, then what they hope to do. Being in a “good place”. Response shift and higher overall QOL results from the supportive environment they live in, the “blessings” they possess, not so much their self-determination or goals they hope to achieve. Bladder and bowel are obstacles but they are manageable.	UM-008; UM-009; UM-010; UM-017; UM-023; UM-039; UM-043; VA-008; VA-006; VA-011; VA-014; VA-017; VA-033; VA-035  Total: 14; Vets: 8; New: 3; Female: 1 Average QOL: 7.89 Average RS: 1.71
Social comparison	Recalibrates their sense of normalcy or acceptance through social comparison with other people or other potential circumstances. Some talk around family or outside forces being their motivation for acceptance and “learning to live” with SCI. More talk of depression and hope that things get better. Could be worse.  Includes: new normal, acceptance, external factors in coping/adapting, social comparison	Social comparison keeps their sense of QOL in perspective. Cite often how they retain their sense of self, how life is neither all good nor all bad, but in the middle. Some find it hard to see things getting better in their lives. A few count blessings and cite opportunities to be with family more. In general, thankful like the group above and speak a lot of balance – how things are balanced in their lives. One cited fears of the future, depression, and being overly dependent on others. Some directly cite bladder and bowel as having a negative impact on QOL.	UM-021; UM-030; UM-041; VA-003; VA-013; VA-015; VA-016; VA-025; VA-029  Total: 9; Vets: 7; New: 3; Female: 2 Average QOL: 7 Average RS: 0.89
Resignation	A clear sense of being “stuck” with little to no apparent response shift. Fear or lack of concern for the future. Focus on loss of independence. Expectations are not redefined, except where they are abandoned. Also may try to ignore their issues or other problems. Avoid social engagements. “That’s the way it is”.  Includes: less positive affect, lack of response shift, sense of loss, passive acceptance	Cite loss of mobility, loss of independence, bladder and bowel more frequently. Show some perspective on things “could be worse” or “could be better”. Talk of acceptance; being able to do what they want, if they wanted to do it. Some family support. In general, like the group above, there is little to no talk of proactive self-determined action to improve life. QOL is through an acceptance of the circumstances, some wishing for improvement, but little sense that circumstances will improve.	UM-005; UM-018; UM-038; UM-042; VA-018; VA-026; VA-027; VA-030  Total: 8; Vets: 4; New: 2; Female: 2 Average QOL: 6.25 Average RS: 0.75

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-005</b> Female White 35/19ysi Vehicular Incomp Para Auto NF No caregiver  QOL: 7.5  Normal Normal	<p>I would have more accidents like the first couple of years after my injury. At this point I know my body more. I'm more in tune with my body. I do wear a pad every day in case there's leakage or something...</p> <p>I do sometimes have problems with leakage and stuff throughout the night. I notice it's more if it's a night when I'm having pain, like some pain in my legs. I don't know what the connection is, but I feel like sometimes I really need to go to the bathroom when that happens. But I'm still able to sleep through [the night]...</p>	<p>...my bowels are in pretty good shape. I'm not on a bowel program and I never have been... The only time I've had that kind of accident is if I had to have a colonoscopy and I had to drink all that yucky stuff. I just couldn't tolerate it.</p> <p>I'm completely cured of bowel issues. Every now and then if I eat something I might not feel so good after it, but one thing I did is I kept a food diary. It was the best advice that one of my doctors ever gave me... I stepped up with my exercise and everything just got moving more smoothly.</p>	<p>A couple of years back I did start having more problems with constipation, but now that's pretty under control. My doctor told me it should get better and it has gotten a lot better.</p> <p>I feel that my bowels are pretty normal other than I do get constipation sometimes, but my GI doctor said that can be a side effect from the spinal cord injury. If I have constipation for several days he'll have me drink something called MiraLAX and that will usually help after drinking that a couple of times.</p>	<p>Yes, I used to have [hemorrhoids] – I've been through all of that.</p>	<p>I try not to cath because I have gotten UTIs and stuff from cathing, so I do try to void by myself.</p> <p>...the first couple of years after my accident, I had to get comfortable with [cathing] and I had to lie down and do it. But my muscles are stronger because I can walk, so now I can just do it from the toilet.</p> <p>I was only getting [UTIs] one to two times a year. This year I've had three or four and my doctor was a little alarmed by it... I don't know if it's I've just been busier this year. I don't know if stress can add to that. I'm not really sure myself about that.</p>
<b>UM-008</b> Female White 63/22ysi Fall Comp Para Private No caregiver  QOL: 7.5  IC Self DigStim, DigEvac	<p>...initially it was probably a lot worse it isn't so much now... I just didn't understand what caused you to have to urinate more or what things you could do to not. Obviously it's not good not to drink enough liquids so it has to sort of be a balancing act. Initially my office was not accessible and so that made it quite difficult but they put an elevator in and but that you know it took some time.</p> <p>Not very often... I would say [I have accidents] primarily if I get a bladder infection or something...</p>	<p>NO REFERENCES MADE</p>	<p>I have not [had constipation]... I do a probiotic every day and that keeps me very regular. Before I did that there would be times when I would be sort of constipated I'm sure probably because you don't get as much exercise. But I do have an FES bike and I think that helps...</p>	<p>NO REFERENCES MADE</p>	<p>Other than I've had bladder infections from time to time but as I said I've always been able to pretty much deal with by just drinking a lot of water and taking a cranberry pill.</p> <p>I probably was cleaning my catheters for longer than I should have because I don't know. My doctor said I could only get 12 a month. I think that's changed now. I don't use them as long.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-009</b> Male White 50/28ysi Vehicular Comp Para Other No caregiver  QOL: 8  IC Self DigEvac	<p>I remember right, shortly after the accident I just kind of was curious if I had a choice of having normal bladder function or being able to walk again was kind of a tossup for me because it's a very overriding thing to worry about.</p> <p>...within the last maybe five years or so I've been getting Botox injections, so I'm no longer taking oral medication for bladder function. Since I've been doing that it's been very beneficial as far as not having accidents and my infection rate has gone down...</p>	<p>I can't think of a bowel accident that's happened outside of my house...</p> <p>as long as I'm able to use a bathroom and I have with me what I need to get the job done then that seems to have worked for me... But as time went on I kind of developed a sensitivity to the very subtle feelings I might have that would let me know that I needed to do something. I guess I have kind of developed a sensitivity to notice what cues I was receiving to let me know that I needed to use the bathroom.</p>	NO REFERENCES MADE	NO REFERENCES MADE	<p>Well, yeah. I mean sometimes it [UTIs] got bad enough that hit got into my kidneys. I've been hospitalized for it a few times. Infection seems to be the big issue. I can't really think of other problems I've had with it.</p>
<b>UM-010</b> Male White 35/16ysi Violence Comp Para Medicare No caregiver  QOL: 6  IC Self DigStim, Suppos, Othr Flush	<p>I used to have a problem where I had a lot of bladder leakage and pressurized bladder... And I had to get tests for that... So I would have these bladder freakouts and I'd think I had an infection...</p> <p>Stress really seems to affect a lot of it... when you panic and think that "My God, I've got to pee so bad," and you start panicking about it so bad you're going to make yourself pee. Where if you kind of just relax and be like "Okay, I'm going to get to the bathroom when I can get to it," you know, and hope for the best...</p>	<p>And then at work if I have problems and stuff, there's times when I've had accidents where I've just had to like, it's like "Hey, I gotta go," and just like leave and not really give much of an explanation or anything because of embarrassment.</p> <p>...you can go out one day just feeling great, thinking "Okay, I'm going to go out and do this and this and this and this," and then like 20 minutes later you like start sweating and you're like "Oh God, I'm going to shit my pants. I can't do anything," and you've... got call it off.</p>	<p>I know if I'm constipated a few days in a row I'm going to have them [hemorrhoids]. But you know, I haven't, I guess it hasn't been a serious problem but I get them.</p>	<p>I get hemorrhoids a lot. Hemorrhoids I deal with quite a bit, that's one of the things. Sometimes I bleed a lot. I don't really check them a whole lot, I don't really use Preparation H... I never had them before I was injured...</p>	<p>So one of the reasons I decided to go freelance is so I can kind of pick my own schedule and I don't have to worry about rushing to get to work at 9:30 in the morning when I have a bladder infection or something like that, you know?</p> <p>I try to drink a lot of water. I try not to drink any pop or anything like that anymore. I take medicine for my bladder, Oxybutynin. I take one of those in the morning, 5 milligrams or whatever it is – I'm not sure what those come in, one tablet.</p> <p>I get a UTI maybe twice a year.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-012</b> Male White 56/12ysi Vehicular Comp Tetra Auto NF Caregiver  QOL: 5.5  IC Self, IC Other DigStim, DigEvac, Suppos, Lax/Meds	<p>There are times I can experience the need to have to urinate that does do some help, but it subsequently...it also can say, "Oops, I've got to run." and it's already too late because I'm already having an accident.</p> <p>I may take sips of water to get by to keep myself from being parched but outside of that I try not to drink more than that because then all of a sudden it introduces the possibilities of having an accident...</p>	<p>I have had some accidents, bowel accidents, and it's usually due to having to take a number of stimulants because maybe I'm fighting an infection and you just...sometimes those stimulants don't give you a clue of when it's going...when you're going to have a bowel movement. And so I've been in my chair and had bowel movements. I've been in bed at night and had bowel movements and not know. Thank God they're very few and far between.</p>	<p>...everybody has that opportunity from time to time when they become more constipated.</p> <p>...you don't know when you're going to go you sit over the commode for seven, eight hours straight. I did it, went through it and probably absolutely did not help my hemorrhoids at the time.</p>	<p>...13 years of bowel program and somebody having to do digital stim and that I've had just atrocious hemorrhoids. ...I finally went and had them taken care [surgically] of, which was one of the best things that I ever did...</p> <p>It made them so bad my doctor that did the surgery said, "I've never seen anything so bad in my life. You should have come to me a long time ago." So they don't have all the answers because they don't have to deal with quadriplegics that much.</p>	<p>...having the straight cath or use a Foley from time to time when I'm away I get a lot of infections and what I've learned through my urologist is a lot of it has to do with just prostate infections, not necessarily urinary infections but those kinds of things I continue to struggle with quite a bit... I actually am on a maintenance program... taking antibiotics 365 days a year.</p> <p>...in the past years it was not uncommon for me to have four, five prostate infections a year...it's not that I've had UTIs. UTIs are much easier on you, 14 days...done...Prostate, you're looking at 30 days plus.</p>
<b>UM-013</b> Female Black 63/36ysi Vehicular Comp Tetra Other No caregiver  QOL: 9.5  IC Self Suppos	<p>When I first started cathing I didn't wear any diapers or anything and then had a couple of accidents, where I was incontinent... I do have the loss of bladder control because of the neurogenic bladder, but it doesn't really affect me because I always diaper myself.</p> <p>I leak... I was scheduled to take Ditropan, but the Ditropan would dry me out and also it constipates me too much... And even when I was taking the Ditropan I still leaked. I didn't leak as much.</p>	<p>NO ACCIDENTS</p> <p>Luckily I don't have the loss of bowel control and that's why I'm mainly speaking about the bladder.</p>	<p>...if I eat stuff that I know I'm not supposed to eat, which I do, I have problems and I know I'm going to have problems. And then sometimes if I check and everything is kind of rocky and hard, I'll take an oral laxative. My doctor prescribed Senna for me. He said I don't have to take it every day, just take it as needed. So I'll take that if I haven't really had a good movement or a good result then sometimes I'll drink a bottle of citrate of magnesia or I may take an enema.</p>	<p>I've got hemorrhoids, so that's causing problems. I just did a colonoscopy last Friday as a matter of fact because I had an episode a while back where... You know, my hemorrhoids do bleed, but this was – I finished my bowel training and I went back to take my shower and it was like blood there. I'm thinking something's wrong here, so I scheduled a colonoscopy and had that done and everything is good with that</p>	<p>I had very few bladder infections...Every time you insert something into your body you're going to have some problems there and the same thing about having something in all the time, so I'm still doing the intermittent catheterizations.</p> <p>...earlier this year when I had a bladder infection I had just gotten off an antibiotic... Then all of sudden I started feeling bad and I thought, well, you need to slow down... And I had to be hospitalized to get the IV intravenously because I had a really bad one.</p>



Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-014</b> Male White 64/41ysi Violence Comp Tetra Other Private Caregiver QOL: 9 IC Other, Transurethral DigStim, Mini- enema	Not very often... About three, four weeks ago. I had a small bladder accident.	When I was eating a lot, I was doing a bowel program every day and then I had a few accidents where I didn't. There was a few times after I cut back on how much I was eating, I cut back to Monday, Wednesday, Friday routine. And then I cut back more on how much I was eating because I had a few accidents doing it that way. So now I do it every three days. That's been going real smooth for me.	NO REFERENCES MADE	Yes, I have hemorrhoids. I don't have, so far, I haven't had a problem with constipation. It's more of a, I eat a prune every evening and the night before the bowel program I have two ounces of prune juices. And that works good for me. It works better than Senokot.	When I have a UTI going on things can, I have accidents more often than others. I just have to deal with it... Two to three times a year.  If the catheter is not positioned right it will leave a sore. So I have to be careful of that and learn from your mistakes and don't let them happen.
<b>UM-017</b> Male White 43/24ysi Sports Comp Tetra Self-pay Caregiver  QOL: 10  IC Self Enema	In 24 years, I can count on one hand how many bowel accidents I've had and the bladder accidents I could – I don't have enough friends and feet and hands and toes so – until I got that right catheter.  Oh I just walked outside. It's been two hours instead of four, but it's 100 degrees out or it's two below and I can't do that. So start paying attention to when I was having my accidents.  I pay close attention to my body. I don't want accidents. I don't want the embarrassment. My goal in life is not to be embarrassed. My goal before this injury was not to be embarrassed.	My bowels, you know, they've always been pretty regular, but here's what I do. I had the accidents right off the gate, and what my family again... they're doing the checking after the bowel program.  Bladder... doesn't bother us as much as a bowel issue... So I see a lot of us struggling there with our bowels and that is one of my main things is just clean. Get all that out of you. Get the juices out of you, because the juices are just as worse as anything else...  When I was first injured, I had a bowel accident that really woke us up to how this could happen and never know it's going to happen.	NO REFERENCES MADE	NO REFERENCES MADE	Took me about two and half, three years to realize I could cath myself being in this C 5-6 level...  I went four years before I got a UTI. The first time I got a UTI, I went to the hospital I said, you know, what do I have to do to never get this again where my testicles swell up like a grapefruit, and he said you know, whatever you're doing, continue to do because if it's been four years before you've had one of the UTIs like this, you're doing great... We were getting three catheters a month back then.  ...so it's been good in that department, not having all the UTIs like a lot of people do struggle with in my position.

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-018</b> Male Hispanic 30/10ysi Sports Incomp Tetra Medicare Caregiver  QOL: 4  Transurethral DigStim, Suppos	<p>...if you're drinking a lot of soda at a movie and you can't just – you know, it's a little more difficult to just step out and go pee and also you have to drag someone with you... I've pretty much had every kind of accident around her and I've kind of got over that.</p> <p>...it is embarrassing if you have a bowel accident in front of a bunch of people or if you have a bladder accident and you're wearing khakis. You know it can be rough... Lately since I haven't had that many accidents it really hasn't been that much of a problem.</p>	<p>You know at the beginning you try and learn how to manage it as best you can and deal with the occasional accident. I personally haven't had a bowel accident in over a year...</p> <p>...the bowel regimen means that I have to take the hotel rooms into account wherever I go and that could be kind of difficult... Also flying might be a little difficult because God forbid I have an accident on the plane, there'd be nothing I could do or nothing anyone else could do and that would be all kinds of mortifying...</p>	<p>Sometimes I'll be blocked by gas pockets or I could just be constipated from diet or medications. That's another thing I have to try and manage with the foods that I eat and make sure I get enough leafy green vegetables, etc, etc. And that takes about two hours, the whole deal.</p> <p>...with my medications I rarely run loose. It's usually a matter of making sure I'm not too constipated... fast food might actually help more than hinder. But I do have to make sure I eat that sort of thing sparingly...</p>	<p>That I've had and that's been more recent. Those are scary. That's a lot of blood, especially when they burst. There's really nothing I can do about them. I do notice that I get them more often when I lie in bed, especially if I don't get up, because there are some days that I don't and then it's terrible for me. So I just try to make sure I get up as often as possible and that kind of keeps them from happening often. But there have been times when I've had then and they've burst and there's been blood everywhere...</p>	<p>Yeah, you get the occasional UTI.</p> <p>And when it comes to bladder, I just make sure I empty my leg bag when it gets full... I just make sure I drink a lot of fluids, you know cranberry juice occasionally or Mannose. Mannose is a product for managing bladder infections; it's a type of sugar... it gets into your bladder and it'll stick to the bladder wall so that E. coli can't and basically prevents you from [getting an infection].</p> <p>I have a standing prescription for an antibiotic... I never take it unless I absolutely need to.</p>
<b>UM-020</b> Female White 52/17ysi Vehicular Comp Tetra Other Caregiver  QOL: 9.5  IC Self DigStim	<p>Generally, I'm continent, and I hate to say that because I don't know that I've been incontinent in six or eight months, but as soon as I say that I'm continent, something happens and I have a problem... But generally, both my bladder and bowel are very, very stable...</p> <p>I get pretty accurate signals through my autonomic system. I know when my bladder is full. I can tell you I get tingling on the top of my head as soon as I have about 300 ccs. I'm able to stay continent as much as I do, and so it's only if I ignore...</p>	<p>I've been incontinent with both my bowel and my bladder. My bowel, again, it happens once a year. Again, I get the autonomic sensation on the sides of my head that tell me my bowel is full so I can tell whether or not it's my bowel or my bladder. I leave and go home and do the bowel program because I know I have to go.</p> <p>...it's just amazing to me how well we are able to train our bowel because I have less accidents or the spontaneous need to go to the bathroom.</p>	<p>Throughout the years I've had problems with the sluggish bowel, et cetera, and for years my nurses have been telling me, "Why don't we try the warm prune juice at night?" Finally, I agreed and that was about two months ago and that has really changed the quality of my bowel program.</p> <p>I go and sit in a shower chair and the nurse does digital stimulation to get me started and throughout the program, but again, at this point I usually start within about ten minutes and on a good day I'm finished in a half an hour.</p>	<p>I definitely have some internal hemorrhoids. They're not as bad as they used to be...</p> <p>Prior to changes in my diet, I would use one or two magic bullets almost every program. Since then I use the magic bullet maybe once every couple of months. The biggest difference has been prune juice.</p> <p>I do have some external hemorrhoids that I have to deal with, but I don't have sensation so they don't really cause me any problems.</p>	<p>I used to have them prior to the urinary diversion in 2005 and since I've had that I may have a UTI once every couple of years. It's that significant of a difference. So again, having somebody here at night, I'm able to do the intermittent cath instead of having the indwelling.</p> <p>...when I was doing the intermittent catheterization, the UTIs were really a pain. I think because of the quality of the care, the fact that I have the 24-hour nursing and the fact that I have the ability to sense when my bladder is full, that's really key.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-021</b> Female White 55/1ysi Medical Incomp Para Other priv Caregiver  QOL: 9.5  Suprapubic DigEvac, Fiber	<p>I had several accidents because they would cath me, and then they'd think, "Okay, you're good for..." They'd say, "I'll be back in like three and a half hours," because they would try to monitor what my routine was. And then two hours later, all of a sudden I'd be wet all over the bed again.</p> <p>And there was another patient there who had a super pubic tube and she told me I should look into that so I started asking about that. Ultimately, [my doctor] put a super pubic tube in me on March 21st. And I still have it right now to this day. It works well for me.</p>	<p>I do it every morning. I go every day... From the time I got out of U of M, I had one accident and it was probably, not probably, I'm sure I did it to myself. I ate...because I usually eat breakfast, lunch, dinner. I really don't snack anymore. I just keep to my meals more than anything... And the one day when I did have an accident, it was my daughter's college graduation and we went out at 10 at night after everything, ate Mexican... And one time in a year, I can't complain about.</p>	NO REFERENCES MADE	<p>I had got a hemorrhoid up there at U of M and I've got it to this day. I have hemorrhoids. I just put a little Preparation H on every morning. It's one of those things, like I didn't want to deal with right now because I asked somebody once, "What can you do?" And they go, "Well, they'd have to operate." I thought, really, I just can't deal with that now. It's not that bad and I don't need any infections or anything. It's bad enough trying to go to the bathroom ...the way I look at it, I'll probably have hemorrhoids the rest of my life.</p>	<p>Yeah, I have concerns about the cathing. Right now, the tubes kind of keeps me free. I can do what I want.</p> <p>I have not had any urinary tract infections or anything. To me, that's another plus. I just drink freely and I drink mostly water. I drink a little milk. I didn't drink pop for a couple of months but I drink a pop. I'll have a pop now and then, still. I'm not a coffee drinker. I just drink a lot more water than I used to but I needed to do that anyways.</p>
<b>UM-023</b> Male White 57/1ysi Fall Incomp Para Medicaid No caregiver  QOL: 5.5  IC Self Lax/Meds	<p>Catheters every three or four hours and of course there's constant leaking, so I'm wearing the Depends diapers, is what I'm wearing right now. That's what I buy and use right now.</p> <p>Oh, I leak all the time. That's why I came to the hospital up here today and they were checking my bladder out to see what they can do about maybe trying to tighten the muscles up on my bladder. I'm on some medication for that already, they found out when I was there today.</p>	<p>It's hard to go places because every few days I'm taking laxatives to go to the bathroom, to have a bowel movement. So just like when I knew I had to come to Ann Arbor today, I either took a laxative a couple of days ago or I'll wait until tonight or tomorrow to take it, so it didn't interfere with me coming up here today...</p> <p>A lot of the laxatives I think give me gas, so you have no control over your bowels, so it can be anytime, even right now you let out gas and you have no control over it.</p>	<p>So I'm still using catheters and right now almost a year later I'm still using catheters and using laxatives to help loosen my stool so I can go to the bathroom.</p> <p>I was trying to find a medium focus there where you'd take something and it would soften it up just enough to where maybe if I had the strength to push I could go without having a mess.</p>	NO REFERENCES MADE	<p>I've had one urinary tract infection, one bladder infection and I think that's it.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-030</b> Female White 45/1ysi Fall Incomp Para Medicaid Caregiver  QOL: 5  IC Other DigStim, Lax/Meds	<p>...you're just used to controlling it and lately here for the last I'd say two months I just can't control it at all... it's discouraging. It's more pride than anything, but I got to look at it and say it's an accident. It's just part of it and I just got to go through it... But the bladder is honestly my only concern.</p> <p>Well it first started when I was in ICU, I couldn't feel anything if I had to go. And then in the hospital, I started feeling that I can go. I know when I have to go right now, but it's making it too be cathed... your bladder is constantly leaking all day...</p>	NO REFERENCES MADE	<p>I had to do suppositories every night in the hospital. Yeah. But the suppositories I don't have to do anymore not unless I really -- if it's really hard then I will. I'll have him do it. I won't let it back up.</p> <p>Suppository is my last resort if just to get it out and get normal, you know, instead of bombed up and have a problem.</p>	NO REFERENCES MADE	<p>I can't cath myself because my hands, so probably the hardest thing is when we have a family gathering and I got to go to the restroom... it takes probably a good 15 - 20 minutes to-- that's what really discourages me.</p> <p>Well, I had a UTI when I left the hospital. And I had an antibiotic for seven days, and then I had one when I was at home but they did antibiotics for 10 days two times, so they wanted to make sure it was completely gone... But the UTIs is what I'm scared of because I don't have full feeling down there, so... I can't tell.</p>
<b>UM-038</b> Female White 36/1ysi Vehicular Comp Para Auto NF Caregiver  QOL: 5  IC Other DigStim, DigEvac, Suppos, Lax/Meds	<p>No [accidents in public] but I have them at nighttime still.</p> <p>I wear a diaper 24/7... I feel like a very, very old person in a diaper.</p> <p>I was leaking so much and cathing so much, I went to my doctor and they did an ultrasound and I couldn't even hold 100 cc's without wanting to go pee again. So she said "Your bladder is having problems, I can help that." And I'm like "Okay, let's do it."</p>	NO REFERENCES MADE	NO REFERENCES MADE	NO REFERENCES MADE	<p>I've had three [UTIs] since I've been home.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-039</b> Male White 42/1ysi Sports Incomp Para Other priv No caregiver VETERAN  QOL: 6  Normal Lax/Meds	NO ACCIDENTS  ...it was demoralizing, like, I'm a single guy. I've been single, I've been divorced now for about going on five years, so, and I've always, you know, been on the market with, you know, single ladies and all that stuff and you know, for the first five months of this injury, I kept my head down. I didn't even look at women...  I haven't had any accidents and that's good, but, when I have to go, then I have to go because I can't hold it in. That's how it is today.	NO ACCIDENTS  just knowing... that I don't have full control of my bowel movement, you know. Just knowing that it's affected me more than it actually, because I haven't any accidents, you know, I haven't gone on myself yet, so, it's, so it's more emotional than it is physical, you know what I mean? So, it's, you know, just kind of a, just one of those things that you constantly think about... I could shit all over myself in front of you, I wouldn't care, you know.	[I was] constipated for the first twelve days [after injury].  And then after that, it's been, you know, pretty, pretty regular. You know, I might, I might even go a day here without going at all. But, it's not like it hurts or doesn't, you know, I don't get sick or anything... for the first couple of months it was really hard, like my bowel movement was super hard. It would actually hurt coming out, it felt like I was, you know, it felt like rocks coming out of there.	NO REFERENCES MADE	I did. I had a UTI... I had a urinary tract infection even before I got injured, and I was trying to deal with it...  I don't even know if it's an infection. I think I just – there's just something with my body now... They couldn't find anything wrong with my kidneys.  ...when I go back to work as a letter carrier, you know, having to pee every hour, hour and a half, you know, that's a problem... so I got to get some sort of medication where I can at least go for five or six hours without having to go pee...
<b>UM-040</b> Male White 61/1ysi Fall Comp Para Other Priv Caregiver  QOL: 7  IC Self Suppos	But as far as being ready to pee, there's no sensations or anything to warn you that, hey, you're gonna start going. And sometimes just touching, when you're trying to get ready to do a bladder drain, just touching and handling will set it off and you'll start peeing so you gotta be ready with the bottle.  I'm just thankful to be here and if I gotta have somebody come in and change my briefs every day, four or five times a day, that's what I gotta do.	NO ACCIDENTS?  The bowels I have no sensations at all. I can't tell what's going on. They've been using a suppository to try to get me on a regular schedule so usually after breakfast they give it to me and then in about 20 minutes they expect to see something happening and that's not always the case. And I'm just now getting to the point where they want to... after I get the suppository, move me to a commode chair and try to help me learn how to go.	NO REFERENCES MADE	Had a little blood at one time...  I had a history with hemorrhoids for a while and that's what I think that was probably from but I only had it one time though, just once in the morning; never saw it again.	It's hard for me to even reach past my knees so my nurses and aides would roll up my pants and band the bag on my leg or they'd come in and band the bed bag at night so Foley was actually quite convenient.  Well they just diagnosed me with having a bladder infection... they started me on antibiotics yesterday for that. I had a urine that looked rather milky and they said it was infected...

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-041</b> Male White 60/1ysi Medical Comp Para Other priv No caregiver VETERAN  QOL: 5  IC Self DigStim, DigEvac, Lax/Meds	Oh, I've had leakage... Sometimes every day. And then I'll go a day or two it doesn't. I went to see a urologist about a month after I got out of the hospital. And he was telling me I might have to start taking a pill for that. And he wanted me to start taking it then, but I told him, I'm already taking so many pills. I don't want to start taking anything if I don't have to. But it's starting look more and more like I might have to start doing that, go that route.	<p>The bowel thing has been a work in progress ever since I was in the hospital trying to get it down right and trying to get it to happen at the same time every day and trying to take the right dose of medication so you're not too hard and not too soft and I don't know... I still don't have the bowel program down.</p> <p>...when I cut my Miralax in half, that's when I cut it down to maybe one accident a week. And then I thought, I'm going to just cut that out completely and see what happens. So I quit taking Miralax altogether... not having accidents anymore.</p>	NO REFERENCES MADE	I had pretty bad hemorrhoids when I first got out of the hospital. And once in a while I was getting a little blood. I had to go see my family doctor when I got out anyway. And I was telling him about it. And he said that's not unusual or unexpected when you first start digitally stimulating yourself and that he thought they'd go away on its own. And that did got away on its own.	NO UTIs  In the beginning, I think, I was in the hospital for two months. And either two or three times during that time, they had to - I think they called it a foley. They had to put in a cath that stayed for a long time, because they were having a whole lot of problems cath'ing me. A couple of times they had blood and it caused trauma, and it wound up I had to have the Coude cath. And every since they switched me to the Coude catheters, I haven't had problems cath'ing myself.
<b>UM-042</b> Male White 55/1ysi Fall Incomp Para Medicare No caregiver  QOL: 2  Normal Suppos, Lax/Meds	NO ACCIDENTS  I have never lost my bladder anywhere.	<p>But I still never think that I'm completely evacuating myself. So it's not fun, and before this happened a couple times I was out places and I've barely made it to the bathroom and – but not really... Not a fun way to live, you know, I'm not 95 years old and I don't like living like this.</p> <p>It's only happened a couple time when I lost my bowels but I was close to a bathroom and it's happened here where I'm in the living room and I can't walk fast because of my leg so, you know...</p>	I would get so constipated probably because of my diet too because I'd have a friend come help me to eat and I had to eat a lot like peanut butter sandwiches which is probably not good for your digestion, plugs you up... I actually had to physically insert my finger into my rectum and pull out my feces. Disgusting, but that's how plugged up I am. And when I went into Heartland, they started giving me stuff, medicine for that and Miralax, you know, you drink; and every once in a while, I done the suppositories.	NO REFERENCES MADE	NO REFERENCES MADE

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>UM-043</b> Male White 33/1ysi Sports Incomp Tetra Other Priv Caregiver  QOL: 6.5  Suprapubic DigStim, DigEvac, Suppos	<p>Like I said, I don't really have any accidents. I feel pretty safe going all day without that. Before when I was in rehab and stuff, I was having accidents once in a while, and that was always kind of embarrassing.</p> <p>The first time you have an accident when you're lying in the hospital bed and you don't understand what's going on. You feel like you need to apologize for it... And they say, "No, it's okay." And you're thinking to yourself, "Well, no it's not okay." It's as if you're a child. But then you kind of figure out that's the way it is.</p>	<p>I was having a bowel routine every day and then I just switched to every other day about a month ago. And ever since I did that, it's been working out real well. Really no issues with it. Everything's been working out great. Really no complications or anything, no.</p> <p>A couple months ago or maybe even six weeks ago, I was incontinent a little bit and having some accidents, but lately, no. I've been wearing regular underwear and not having any accidents or anything like that. It's been a lot better.</p>	NO REFERENCES MADE	NO REFERENCES MADE	<p>Yeah, a lot of UTIs, and you get those constantly, especially from the intermittent cath.</p> <p>I haven't had one in the last five weeks or six weeks or so [since getting a suprapubic tube]. But in the last five weeks, I haven't had a UTI. I think it's working out pretty good. It's a lot more sanitary way to do it.</p> <p>It's difficult. The suprapubic catheter is definitely a huge change or huge positive rather than the intermittent cath. I would definitely recommend that 100 percent at least at first.</p>
<b>UM-044</b> Female White 27/1ysi Medical Incomp Tetra Other priv Caregiver  QOL: 7.5  IC Other DigStim, DigEvac, Suppos	<p>NO DIRECT REFERENCES TO ACCIDENTS</p> <p>Yeah, if you drink less water then you're less likely to have bladder leakage...</p>	<p>Like I have no control over it... I mean I could be shitting my pants right now and I don't know it, you know.</p> <p>...as a young woman, like I can't be intimate or anything like that because I don't know what's going on... I can go to do something, and I could be in shit all over the place...</p> <p>I used to in the beginning more I would say because I think it's – what I've found is once you like get into a new routine, a new process, it takes you awhile for your body to adjust.</p>	NO REFERENCES MADE	NO REFERENCES MADE	<p>...the urine can tell you a lot of things, like if you're dehydrated or if you have a UTI because you know, like if the diaper, the thicker it gets then maybe you have an infection... where you want it more clear and... runny.</p> <p>Like you know usually UTI's are painful. Well, I don't have any sensation so if it's – if I have signs of other things of a UTI well, I need to know before, so I can get it taken care of...</p> <p>I've had you know, several UTI's, mostly in the hospital. I've had maybe one or two since I've been home...</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-002</b> Male White 45/20ysi Vehicular Incomp Tetra VA Caregiver  QOL: 8.5  IC Self DigStim, DigEvac	<p>Then you're always worried... if I start coughing or laughing I might you know have a leakage.</p> <p>I wear an external catheter and a leg bag for leakages which works out fine unless you're coughing really hard, and then you have incidences of leakage and whatnot.</p> <p>...the main concern I always have is you know, am I going to have a bladder control problem today? Especially, like this time of year I have a lot of coffee with, you know how it is, it comes out when it's cold.</p>	<p>Bowel accidents, I think in the 20 years I think I've had two. I've been very lucky on the bowel side.</p>	<p>I mean everybody gets constipated occasionally, but nothing, nothing, I've never had an impaction or anything like that.</p> <p>I mean everybody gets constipated sometimes if you don't drink enough fluids, fiber, roughage, or whatever. Generally if I go a day without going, then next day I make sure I grab an apple, or some raisins or something, get the fiber moving and back to normal.</p>	<p>Hemorrhoids, yeah, but I never really thought it would be a complication. I don't feel it so it wasn't really a big deal.</p>	<p>No, just you know UTI's and kidney stones and stuff like that, which all go hand in hand with intermittent catheterization, or at least it seems to be. That's even gotten better with the more, not having to reuse catheters.</p> <p>All it takes is a few little bugs or whatever you want to call it and next thing you know. Yeah I think I went from probably having three or four UTI's a year to having one UTI a year so definitely better.</p>
<b>VA-003</b> Male White 35/13ysi Vehicular Comp Tetra VA Caregiver QOL: 8.5 Urinary Diversion/Ostomy Suppos	<p>Well once you get the UTI, that's when the leakage would start. Once I got away from that intermittent cathing thing, it kind of all took care of itself.</p> <p>I did intermittent caths for three years.</p>	<p>NO REFERENCES MADE</p>	<p>There's some, I mean you get your bouts of constipation occasionally if you have, if you don't drink enough water or depending on what you ate that day or whatever. It's a learning curve. You just got to figure out what works for you and stick with it.</p>	<p>NO REFERENCES MADE</p>	<p>It's been better. It's been a ton better. Rarely is, I've gotten very few UTI's since. Maybe once a year, as opposed to once every three months when I was intermittent cathing.</p> <p>...I have had one revision of the stoma. It was probably a year or two after they put it in. The fascia closed down around it. So they did a revision to open it back up. Other than that I've had like no problems</p> <p>...Right. Well that and I was getting UTI's all the time. I was getting bladder stones. It was complication after complication.</p>



Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-004</b> Male White 43/10ysi Sports Comp Para VA No caregiver  QOL: 9  IC Self DigStim, DigEvac, Suppos	<p>...I ended up losing tone with my bladder. I had a bladder augmentation surgery done approximately 4 years ago where they removed a section of bowel to I guess add capacity to my bladder. Since then I haven't had any problems with incontinence or anything. It's worked great.</p> <p>I was basically, it came to the point where I had to cath myself about every 2 hours. I really had to monitor my fluid intake. Incontinence issues, bladder accidents, that's what led up to that.</p>	<p>NO ACCIDENTS</p> <p>Going out, I wouldn't say it affected me as far as going out, but it was always in the back of my mind lingering like what if I have a bowel accident, blah, blah, blah. That was my biggest concern was having an accident.</p> <p>...Actually I've been pretty lucky. I've never really had an accident.</p>	<p>...My diet, I wasn't really eating anything because I was concerned about, not necessarily having an accident but I was concerned that maybe there was too much stool built up.</p> <p>...Yeah occasionally, that was a huge issue about a year ago.</p>	<p>Hemorrhoids have been an issue.</p>	<p>I was having a ton of UTI's too. And the UTI's I wasn't getting all the tell-tale fever, the biggest thing I was having where I would know I had a UTI was the incontinence.</p>
<b>VA-006</b> Male White 57/36ysi Vehicular Comp Para VA No caregiver  QOL: 7.5  IC Self DigStim, DigEvac, Suppos	<p>...the wife would complain that when she stopped sleeping with me, oh you always pee in the bed, which I didn't always but I certainly did once in a while.</p> <p>...I've got real wet at times where I'd have to leave, go home and change, probably not even go back.</p> <p>...forget about going to the bathroom because then you really have big problems with urine on your body... it gives me a couple minutes to say, "Hey pause this meeting for a minute I got to go check something out." Then I look down there and there's only a couple drips, it's not a big deal.</p>	<p>And then I go to the VA hospital... they would take you to the bathroom like every other day and I was a young 21 year old, I said, "Hey, I got to go twice a day every day" you know and so when I'd be pooping in bed and stuff I'd say, "I need to go every day, not just every other day".</p> <p>I had to go and use the bathroom there because I started going. It was a mess as far as cleaning up in there, in a different place... It was also terrible, some strangers would be walking in and out and saying, "Oh my God what is happening in here?", and I feel even worse then.</p>	<p>I guess the main thing is the time period right now between when I'm emptying my bowels [getting longer between bowel movements].</p>	<p>And as far as hemorrhoids, I think I might have had minor ones. When I use digital stimulation and I feel like once in a while it seems like it's different, but no doctor has ever diagnosed hemorrhoids or anything so.</p>	<p>I get bladder infections once in a while, maybe once a year, two times a year. They're never very serious, just have a lot of water, beer, or cranberry juice definitely works about the best. You know and it blows it out and I'm fine.</p> <p>I had a real bad one last year actually... It must have been pretty inflamed, because it was infected. Apparently the catheter must have went in just the right way where it broke open a capillary or two. So, there was a bit of bleeding in the bladder and it was clotting up. So when I put the catheter in, the clots would get in the hole and it wouldn't let the urine out...</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-008</b> Male Black 48/26ysi Vehicular Comp Para VA No caregiver  QOL: 10  IC Self DigStim, DigEvac, Lax/Meds	<p>I just had a urodynamics test about two months ago because my urologist wants to, because I'm not holding enough, my bladder is not big enough. I get up to 300 cc's and then I have to either cath myself or it's going to come out automatically so I have to wear a leg bag all the time.</p> <p>...it's a way of life and the embarrassment just went out the window. I don't get embarrassed easy like I did. If something happens I go home, clean up myself, then come back.</p>	<p>Initially I was 22 years old and it was really hard because you don't know when you have to go to the bathroom between your bladder or having bowel movements.</p> <p>It wasn't not being able to walk. The hardest part for me was the bladder and bowel because there were, I'm young man, a grown man and you don't know when you're going to have a bowel movement. You're peeing in the bed. You're having bowel movements on yourself.</p>	<p>...at least 3 years, 4 years I was getting really bad stomach aches. Sometimes it would hurt for two days and I would never go to the hospital you know, and it finally goes away... the pain was so bad that day I just couldn't take it. So I thought something really going on and it ended up just being constipated. [The doctor] explained to me that even though I'm getting the stool out from the lower bowel, there's still some in the top. With the spinal cord, we can't push so that kind of creates a problem...</p>	<p>NO REFERENCES MADE</p>	<p>...a lot of times I wear the leg bag because I don't like cathing myself in every place because of germs and the bacteria and stuff. You end up getting UTI's and stuff. So I really try to be careful on that.</p> <p>I used to get the UTI's at least once a year, maybe twice a year. I think when I started changing where I cathed myself at... and I think this is why spinal cords got so many UTI's, because they always taught us, they gave us catheters and you could rinse off and wash the catheter.</p>
<b>VA-011</b> Male Black 48/16ysi Vehicular Incomp Tetra Auto NF Caregiver  QOL: 9.5  IC Self DigStim, DigEvac, Suppos	<p>I can feel it, like I'm voiding and it's going into my bag but before that happened it was like, man my head is, I was feeling a little woozy. Not dizzy, but I would start sweating and I was like there has to be a better way to do this. And like I said coming to realize that I was experiencing some of the effects of autonomic dysreflexia, because what was happening was my bladder was so full that it was forcing its way out... So again, for health reasons and cautionary reasons I went to the cathing and intermittent cathing and that's worked ever since then.</p>	<p>About three years in and my schedule became a lot more, got a lot busier... my days were getting longer. So... I had an accident and it was like, there's got to be a better way to do this.</p> <p>I can stand so if I'm standing to get, to do something, to grab something, whatever, all those things help to move your bowel down... accidents started to happen so I said I got to go do this every day and make sure I'm empty. So that I can have the confidence throughout the day, I don't have this in the back of my mind that I'm going to have an accident...</p>	<p>That's probably when I haven't drank enough water the day before and my stool is very bulky and hard. I don't mean to be too graphic.</p> <p>Fluids, yeah keeping my water up. That's an important piece, that's worked for me. Then take some Benefiber or things like that just to try to get the fiber in my system. And that helps a lot.</p>	<p>Make sure to get my fiber, things like that to manage the quality of the stool if you will. But yeah hemorrhoids is an issue because, well I don't know if it's hemorrhoids, but occasionally my wife will tell me that I do get some bleeding. That usually a hemorrhoid that may have broken in. I usually can, I can always, I can almost tell you when there might be some bleeding.</p>	<p>...it was very uncomfortable to put a catheter in me. It hurt basically.... It made a big difference for me because it has allowed me to manage my bladder much more regularly. Certainly I've cut down on urinary tract infections, UTI's. It's given me a lot of independence that I hadn't even considered before.</p> <p>...for health reasons and cautionary reasons I went to the cathing...</p> <p>I'm not using the same catheter over... one time use then you get rid of it. So it certainly does cut down on the chances of infection.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-012</b> Male White 56/27ysi Vehicular Comp Para Other Priv No caregiver  QOL: 9  IC Self, IC Other DigStim, Suppos	<p>So it just controls really how you live your life, the bowel and bladder. It's amazing. You might choose to do things differently just because of how the bowel and bladder will be impacted by the decision... It was a problem about six years ago. It was frustrating because you would have it and you would have to go home from work.</p> <p>I did have the botox done, so that helped me so I didn't have to take the meds with the spastic bladder. So I am probably going to have to do that again because my bladder is starting to leak again.</p>	<p>...the bowel has been the biggest challenge for me in the almost 27 years I've been in a chair.</p> <p>Well with the bowel, it's really been the big challenge for me. It's just, I would say the last six years, seven years, and inconsistencies with it. I've had bacteria build up in the small intestine. It took us three years to find that out. I kept having these accidents and we couldn't understand why. It was because I was constipated, that was part of the problem.</p>	<p>It's just, I would say the last six years, seven years, and inconsistencies with it. I've had bacteria build up in the small intestine. It took us three years to find that out. I kept having these accidents and we couldn't understand why. It was because I was constipated, that was part of the problem.</p>	<p>Oh, I get, I do get hemorrhoids. Blood comes out and you bring it up to your physician but they have never seemed to be too alarmed by it. When you're cathing and doing dig stim as often as we do it, you wonder if the bowel was really designed for just putting our fingers up there to do that.</p>	<p>I switched catheters. I used to use a catheter where I would have to lube it, then clean it and reuse it. I use a catheter now that comes lubed and I use it once then I throw it out. I don't have as many UTI's as I used to have because of that... Why didn't I know about this stuff 10 years ago?</p> <p>With the bladder, the goals are UTI's, preventing UTI's and leaking. I would say those are the two priorities probably for a person with a spinal cord injury.</p>
<b>VA-013</b> Male White 56/37ysi Fall Incomp Tetra VA Caregiver  QOL: 8.5  Suprapubic DigStim, Lax/Meds	<p>Difficulties, I was just having problems like crapping your pants or pissing your pants because you blow a condom. God I used to do it all the time.</p> <p>Nowadays I don't have problems except for when my catheter backs up... Once, twice a year.</p>	<p>I have not had an accident since I quit using the suppository [eight years ago].</p> <p>I used to use a suppository in the morning and sometimes people didn't know if you were done right or if you were finished. Sometimes I would get up and go to work and halfway through work I would crap my pants... And now I'm not using a suppository because my caregivers felt that I didn't need to have it because they could do it without the help of that and still evacuate my bowels completely.</p>	<p>No, just constipation sometimes... I take milk of magnesia pills. I asked the doctor to give me some Docusate which is a stool softener. And then I just watch what I eat.</p>	<p>NO REFERENCES MADE</p>	<p>...my bladder started getting a thick wall because it's using, it's pushing out and it's forming like a muscle and it's pushing out the urine so the wall would get thick and it wouldn't empty completely and I was getting a lot of infections. So I went to a suprapubic which is a catheter through the wall of the stomach into the bladder.</p> <p>I would know I had a UTI so sometimes... I'd call my doctor and say I got a UTI and he'd call me in a script for Cipro.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-014</b> Male Hispanic 62/33ysi Vehicular Comp Para Other Priv No caregiver  QOL: 8.5  IC Self DigStim	<p>I do have a leakage problem when I'm making transfers. From out of my car to into my chair or making a major transfer, I need to use all my abdominal muscles and I will have a leakage problem sometimes. Not all the time. But for the most part it stays fairly dry.</p> <p>When I'm not healthy if I cough or sneeze or laugh my bladder will leak and sometimes it could leak a lot or sometimes it could not leak at all or it could leak a little bit. So it depends on how healthy your bladder is.</p>	<p>The only difficulty is having an involuntary bowel movement in public... And you never overcome it because you have this subconscious feeling that oh people are looking at me or oh they're pointing fingers and this and that. And it's always a problem and you'll never get over that.</p> <p>It wouldn't be like I had an accident instantly...if there's anything in the colon, the upper or lower colon it's coming. If you didn't do a good job when you were sitting there the first time around, it'll finish the job for you in unflattering terms. So it's inconvenient.</p>	NO REFERENCES MADE	NO REFERENCES MADE	<p>I used to get a lot of UTI's when I was, before I was able to get sterile catheters, recycling and washing them and this and that. You really can't clean catheter as well as you can get one out of a sterilized environment. And so that was the problem. And usually my hands are always dirty because these are my feet. And the floors are dirty and it gets on my gloves and my fingers and I have to use my fingers.</p> <p>. I know right now I have a UTI. I've had it for about 3 months. I was hoping I could get rid of it but it hasn't gone away and it's still here.</p>
<b>VA-015</b> Male White 67/13ysi Vehicular Incomp Tetra VA Caregiver  QOL: 5  Transurethral DigStim, DigEvac, Suppos	<p>I stood up and it ran down my leg. I said, "Well we missed that one." We went in and finished draining it off. The next thing I know, it's just weird sometimes.</p> <p>Sometimes it is unpredictable. Because sometimes it comes all the way up and all of a sudden it goes all the way back down.</p>	NO REFERENCES MADE	NO REFERENCES MADE	NO REFERENCES MADE	<p>A UTI. Yeah that's why they want to raise that tube. This is the third one I've had. Well the second one I've had within a month.</p> <p>I squawked and screamed and yelled and everything. And finally we got a hold of one nurse and she said take it and cut right below the balloon and that way it will let everything out of the bulb so that if it decides it wants to push itself out, it will. And I did that, the next thing I know it came out.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-016</b> Male White 58/28ysi Vehicular Comp Para VA No caregiver  QOL: 7.5  IC Self DigStim, DigEvac	<p>But I didn't have the problems of leakage or anything until I got this lymphedema. Now when I got bed and wake up and decide to go to the bathroom I have to go fast.</p> <p>...you'd bend over and reach for something, putting pressure not thinking and you get up and go wow now I'm wet.</p> <p>But what people don't know is I always had the same exact change of clothes in my car or in my van. So when I went out and actually had problems I could go out in the car or van and change in the front seat...</p>	<p>I mean not to be rude but I shit all the way up my back. Like three or four times between the canned mushrooms and corn.</p> <p>I guess my buddy doesn't like me when I shit my pants and change my pants on his floor. But I put blue pads down dude, shut up. But he's my friend for 35 years so screw you. He's like well quit pissing your pants! Well then come over here and help me yank them off! But you know it doesn't.</p> <p>I've had a few accidents in my life but not until, God I haven't had a problem in 4 or 5 years.</p>	NO REFERENCES MADE	NO REFERENCES MADE	<p>So not being gross, I find that being with a clean catheter and my clean hand, if take one little dab and I put my finger on the head of my thing and put it in it goes in like grease lightning. That's it, better by far. And then you've got the germs but it's my germs this way. So that just makes it real easy. You have to make sure your hands are clean, other than that I haven't had, I've had one bladder infection in 28 years.</p>
<b>VA-017</b> Male White 45/26ysi Vehicular Comp Para VA No caregiver  QOL: 8.5  IC Self DigStim, DigEvac, Lax/Meds	<p>Yeah I mean, but I don't know anybody in a wheelchair that doesn't [have accidents]. And it's not like I have them every day or not even every week or not even every month... Sometimes I'll leak, like I don't get very many UTI's but if I do get one I can't hold it as much. I got to cath myself constantly. It seems like almost every 2 hours I have to cath myself or else I'll leak. But if I'm leaking I know it, I can feel it. I can feel like I'm hot and I have to go. So hopefully I can go find somewhere I can cath myself.</p>	<p>Like a bowel accident, maybe once a year if that.</p> <p>I can only think of... two instances where I had an accident that was like crazy and I will never forget because it was embarrassing as hell. We were on our way to a four wheel drive jamboree with a whole bunch of people... And all of a sudden I had to go, and it was bowel care stuff too. And I ended up trying to get inside my friends house which was a mobile home and get into their bathroom which was too small and it was a disaster...</p>	<p>Yeah I get constipation all the time. I take stool softeners for that... I pretty much take them on a regular basis, stool softeners.</p>	NO REFERENCES MADE	<p>Well you have to cath yourself 4, 5, 6 times a day so. Especially with me, I have strictures in my urethra or however the hell you say it. So that makes it even harder to cath myself because the catheter is going hard.</p> <p>Two or three times a year maybe. But I don't even go to the doctor when I get them [UTIs]. It seems like I only get them for a day, maybe two and they just kind of go away by themselves. So I don't really even know if I have one or not. I just assume I do because you can kind of just smell it...</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-018</b> Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver  QOL: 7  Urinary Diversion/Ostomy DigStim, DigEvac, Suppos, Lax/Meds	<p>First couple years they used a condom catheter and then every now and then they would have to catheterize me with a regular catheter.</p> <p>Same story worked pretty well at first for the first 20-some years then the bladder went to hell in a hand basket...I drank so much that it stressed my bladder out that I kept gets pockets of infection. So I had them do a urostomy which I wish I would have had done in the beginning because it has worked out perfectly fine and it has been working for the past 20-some years.</p>	<p>I have no really outside life due to concerns over accidental bowel movements. So I am putting in to get an elective colostomy done.</p> <p>Well you never know when you're going to have to go to the bathroom. It could happen at any time. So it's very, for me anyway, it takes me days to plan out if I'm going to go anywhere...</p> <p>But I always have to plan bowel care and bowel programs and throw in extra ones or just go out and take a chance, which really is not very conducive to having a good life experience.</p>	<p>Oh yeah, you get constipation, diarrhea, and just the lack of not knowing when you're going to have to go to the bathroom.</p> <p>I just don't, no, not really. I have never really had a problem with constipation because I take milk of magnesia three times a week.</p>	<p>I guess I do have a small hemorrhoid. Other than that I haven't had any problems.</p>	<p>...I had the urostomy done after 15 or 20 years of being injured. I think it was more like 15.</p> <p>Bladder infections were a pain in the ass. They told me I had to drink more fluids. So I drink today probably 2 or 2.5 gallons of liquid a day. But I did that when I had my bladder and that stretched out my bladder and caused pockets in the muscles of the bladder which held infections and I kept getting constant infections in my bladder. That's why I had the urostomy done...</p>
<b>VA-025</b> Male White 65/26ysi Vehicular Incomp Tetra Auto NF No caregiver  QOL: 6  IC Self Mini-enema, Lax/Meds	<p>And that worked well for a number of years [voiding on his own] but then after I would say maybe ten years, maybe even less than that, I began having urinary problems and now I use a catheter...</p> <p>All of a sudden I'd go to bed and... I'd noticed I'd wet myself... Of course, I went to the urologist and he said, well, that's often the case with incomplete injuries. Some people that do re-gain the ability to void on their own after a number of years that ability goes away.</p>	<p>...a difficult part of being in a wheelchair is you don't fit into a lot of bathrooms and by the time I had had the urge to go, in just a matter of minutes and just shit would let loose. And it would just be too late... it could be just extremely embarrassing if you're out and about and it happened to you.</p> <p>... it was kind of devastating because here you were an adult and you're back to your young childhood days of basically shitting in your pants... As long as I use the suppositories I would have occasional accidents.</p>	<p>NO REFERENCES MADE</p>	<p>Lately it's been a lot of blood. I seem to go through periods about every couple of months where it seems that an awful lot of blood following a bowel movement.</p> <p>There still is quite a bit of pain from my hemorrhoids that day of my bowel movement... the reason being is I have a hard surface shower chair and if my hemorrhoids haven't really receded enough it's kind of like sitting on a golf ball. I just don't want to do it. I just want to avoid it at all...</p>	<p>I've been very fortunate especially with using catheters and that but I have not had very many urinary tract infections. I would say I had shoulder surgery a year ago, let's see, February 2013, rotator cuff repair. When I was in the rehab facility the nurses were I thought poorly trained as far as using a catheter and they sure didn't use enough lubrication. Anyway, I had a number of urinary tract infections in the couple of weeks I was there but I think I had just one since then and that was just about a year ago.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-026</b> Male White 64/45ysi Vehicular Comp Para VA No caregiver  QOL: 9  IC Self DigStim	<p>I for some reason got it in my head that I wasn't peeing enough. I went to the U of M and got an operation, I can't remember what it was called. They went in and cut, the sphincter I think it was maybe, I'm not too sure anymore. This was back in 1990, the early 90's, to help the flow of the urine to come out better. As it worked out, it didn't work too well. So I started cathing. Now I leak a little bit so I never should have got the operation...</p> <p>Just make sure that my bladder is empty and that I don't have any problems...</p>	<p>Stick to the plan, start cathing, try not to go digital like I do every three days. Try to go at least every two days. Try not to shit in your pants, I guess.</p> <p>[Regarding bowel incontinence] In the very beginning a long, long time ago but no, nothing.</p>	<p>That really sucks. I tried different ways to manage it and the only thing that, suppositories would never move it down, the only thing that works now is digital. And it doesn't move down that well so I only go about every three days.</p> <p>...the importance of fiber so there's no constipation. That's probably why it takes so long to move down because I was constipated for a lot of years and I don't know. I guess that's probably it. Just stick to the plan...</p>	NO REFERENCES MADE	<p>I didn't start catheterizing until after, well I didn't catheterize for the first 20 years and I should have... I don't have too many problems, an occasional infection from time to time, but nothing for quite a while.</p> <p>A few [infections] throughout the years. Not so many since I've been cathing.</p> <p>I've probably had throughout my life, probably about 3 or 4 infections where I didn't come to the VA and about 3 or 4 where I did and got antibiotics.</p>
<b>VA-027</b> Male Hispanic 72/29ysi Fall Incomp Tetra Medicare Caregiver  QOL: 4.5  IC Other Colostomy, Lax/Meds	<p>Then with the bladder it was the same thing [lots of accidents]. It's kind of hard to judge it at the beginning with the way your output was. After a while you start getting used to it, like what you drink. You have to be careful what you drink if you're out doing something, like limit your drinking. The more you drink, the more frequently you're going to have to relieve yourself.</p> <p>Leak? Maybe in 30 years maybe twice, that's about it.</p>	<p>It was rough trying to get used to it because I was having a lot of accidents all the time trying to get used to the bowel movements. Sometimes I would go and sometimes it wouldn't and then you would have accidents when you go out.</p> <p>...in the past 2-2.5 years I had a colostomy and that made a lot of difference. No more accidents...</p> <p>...[the colostomy] was only supposed to be temporary but I decided to keep it. It's a lot better. No more accidents.</p>	NO REFERENCES MADE	<p>Oh, hemorrhoids and enemas that I was taking to help with bowel in the morning... they would cause a lot of hemorrhoids on there too. That was one of the side effects.</p>	<p>Yeah, I get some [UTIs].</p> <p>I'm usually pretty good. I could go years with the bladder and only sometimes it will get infected, maybe twice a year. Three is really too many but it happens sometimes, three times a year.</p> <p>...still don't know what happened. I was putting the catheter in and all of a sudden nothing but blood was coming out.</p>

Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-029</b> Male White 55/17ysi Violence Comp Para VA No caregiver  QOL: 6  IC Self DigStim, DigEvac, Lax/Meds	Occasionally, especially if I'm up late, one thing is the compression socks I have right now I don't think are high enough. Because my feet will swell if I'm up all day long, my feet will swell up at the end of the day. So there's a lot of fluid there. If I just jump in bed for the night, I'm going to go. Sometimes I wake up, usually I wake up. But sometimes I don't. I use chucks on my bed. I learned early on that you have to have protection there.	When I'm prevented from going somewhere it's usually because I've had an involuntary bowel movement at the last minute or something while I'm getting ready... Because sometimes, you can eat right all the time, but sometimes your body just does its own thing and we don't know why.	NO REFERENCES MADE	NO REFERENCES MADE	I can't think of anything [complications] other than the occasional bladder infection.  Yeah, I don't know. I don't know what I've done that's different. For years I reused catheters and I would get an occasional UTI. But now that I'm using strictly sterile catheters I haven't had that problem.
<b>VA-030</b> Male White 64/21ysi Medical Incomp Tetra Other Priv No caregiver  QOL: 8  IC Self Straining, Lax/Meds	It's a pain in the neck. I never know what's going to come out of either end or when. Sometimes my urinary tract or my bladder just splurts it out and it leaks all over. I have to carry a urinary pad. Most of the time by the end of the day my clothes smell like urine from the leakage.  It used to be that the urine would, now it's leaking out whenever the bladder fills and I can't control it. So even if I go to urinate it starts... dripping in my clothes and going everywhere.  The bladder just keeps getting worse and the doctor talked about maybe botoxing the bladder if it doesn't get better.	As far as the other end, I'm constantly constipated or like yesterday, finally everything I had been taking loosened everything up and I had to go to the bathroom 3 times and ended up cancelling a visit with my brother because I thought I was going to have diarrhea. That pretty much sums it up. It has been irritating and aggravating from both ends.  I came close yesterday [to having an accident], but no. Well I have had a few now and then.  If I could get to a place where it was such a bad thing and I knew when I was going to get the diarrhea, I would be alright.	Then bowel movements, it goes from hard little balls coming out where I have to push and push and push, to yesterday where I'm going four times and thinking, you know. I'm trying to find some kind of a balance but it just doesn't seem to work. Now I've cut back on everything that I was taking. So it's a balancing act that I haven't been able to get right.  ...I'm lucky if I go every 3 or 4 days, sometimes it's longer. Like now since I'm cleared out, it might be a week. Ok and if I don't come up with the right routine, it would be hard as rocks again...over the last five years the constipation has gotten worse.	NO DIRECT REFERENCES MADE  I mean sometimes I just have to push and strain and blood comes out and everything.	Well the biggest problem I've been having lately is that my sphincter muscle, I guess, makes it hard to get the catheter in. So I have to have botox for that now. I've had it done twice in the last year and a half.  Well, I get a lot of UTI's. It's probably, well it's better now. It was about 4 or 5 times a year, but now it's down to 2 or 3. And I've stopped drinking coffee because that's seemed to aggravate it. I stopped drinking a lot of pop because that seemed to cause it. Lately since I've been drinking mostly water that seems to be better.



Subject	Bladder Incontinence	Bowel Incontinence	Constipation	Hemorrhoids	UTI/Cathing
<b>VA-033</b> Male White 69/27ysi Fall Comp Para Medicare Caregiver  QOL: 7  IC Self DigStim, DigEvac	NO LEAKAGE UNLESS ACTIVE INFECTION  No, I've been fortunate in that. Unless I would get a kidney infection or a bladder infection, I was alright.	. I do a digital stim and make sure that I emptied myself so that way I have a better chance of not having an accident during the day.  So sometimes it just hits you all at once like the flu or diarrhea or something you ate. Then you've got it all over and you have to take your clothes off and clean yourself to get all off of you from that.  When you can't feel to know when you have to go, the only thing I have to rely on is my stomach. If it gurgles or something then you know there's a problem and hopefully you can get to the bathroom before it happens.	You just have to make sure if your bowels are constipated, you have softeners and try to stay away from certain kinds of foods so you don't end up with the stomach thing. All you can do is pray and hope for the best.	Oh, yeah. I have hemorrhoids now. I had a colonoscopy done in the hospital and they said I had inner hemorrhoids and outer. I had them operated on once but that was a pain because of the situation. You have to go in there and do stim to go to the bathroom and you're going to tear stitches or anything. That was a problem too, but I got through it.	I self cath so to go out somewhere I have to make sure that I've allowed myself enough time between there that either I can cath somewhere in a bathroom there or cath in my van or either come home if we're going to make it back home before I have to go to the bathroom.  But you need a table in there [public restroom] because you need to set your stuff on it and if not you're going to be setting your stuff on the floor and the germs and all that stuff, you've got to try to stay as sterile as you can. And if you don't then you end up with the bladder infections and stuff. I had a lot of bladder infections...
<b>VA-035</b> Male Black 62/28ysi Violence Comp Para VA Caregiver  QOL: 10  IC Self Colostomy	Oh yeah, I've had accidents with my bladder when I went over 4 hours before I straight cath myself. It all depends on how I drink. I could drink through the day and do good with my straight cath, but at night time I have to stop drinking at night. If I don't, if I go to sleep when I do wake up I will be wet.  I started wearing pull ups now instead of going to bed with my underwear on.	NO DIRECT REFERENCE MADE  I have a colostomy bag, but I didn't have one at first.	NO REFERENCES MADE	NO REFERENCES MADE	...you have to stick it down there slow, you don't want to stick it where you hit the other way because if you go the other way blood is going to come out. So if you do that you're going to get kind of messed up for 3 or 4 days and you have to go to the hospital and then your penis be bleeding all day and all the next day.  Well I had bladder infections... maybe once a year.

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-008</b> Female White 63/22ysi Fall Comp Para Private No caregiver  QOL: 7.5  IC Self DigStim, DigEvac	NO REFERENCE	Yeah [Redacted Proper Name] helps me like I had a torn rotator cup a few years ago and I couldn't use that arm for six weeks. Obviously I couldn't transfer or I even had a really hard time catheterizing myself. But I did sort of figure out how to manage it but he had to help me transfer because I couldn't.  I suppose he could I've never had to.	He vacuums the rugs for me because it's really hard for me. I just can't do a very good job.	NO REFERENCE
<b>UM-010</b> Male White 35/16ysi Violence Comp Para Medicare No caregiver  QOL: 6  IC Self DigStim, Suppos, Othr Flush	Uh-huh, yeah. I have a urologist I talk to if I'm feeling really bad but I don't, I don't really have anybody else that I go to about it.	NO REFERENCE	Mm, not really. I mean the closest thing probably would be I live with my parents. You know, my mom and my stepdad, but you know they don't really assist me with any of that stuff. They help me with laundry when I have an accident or something, but	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-012</b> Male White 56/12ysi Vehicular Comp Tetra Auto NF Caregiver  QOL: 5.5  IC Self, IC Other DigStim, DigEvac, Suppos, Lax/Meds	NO REFERENCE	Yeah, they're...I've had...right now I have four of them. Two of them do bowel program and shower. I have two that do my nightly tying and cathing. One of the two that do my bowel program also helps me out during the week to get me up and get me ready for the day and get me off and running.	NO REFERENCE	NO REFERENCE
<b>UM-014</b> Male White 64/41ysi Violence Comp Tetra Other Private Caregiver  QOL: 9  IC Other, Transurethral DigStim, Mini- enema	NO REFERENCE	Help me keep track of the time for cathing.  It's all done in writing, charting for, my routine is, and as long as they stick to that routine it works good for me.	I have a set routine. They just do their job.  They expect more of a relationship or less which should be more professional than trying to make, build a relationship that's not supposed to be.  It's all done in writing, charting for, my routine is, and as long as they stick to that routine it works.  I've asked my wife a question before and my nurse will answer out of turn and I have to get after her about it. I have to direct my question to my wife so the nurse doesn't speak out of turn, be more direct about things.	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-018</b> Male Hispanic 30/10ysi Sports Incomp Tetra Medicare Caregiver  QOL: 4  Transurethral DigStim, Suppos	<p>Yeah, it's something my mom taught me to do, is to be my own advocate. And I kind of just followed her example while I was in the hospital.</p> <p>Well, I get all that paid for through Medicaid and there's a program called the My Choice Waiver program and it pays for however much attendant care you need... And with that I work through like an escrow company that handles all the payroll and then I just pick my employees and the fill out paperwork and they work for me.</p>	<p>Well, she'll drain the bag and make sure that it's placed right when I get up from my chair. Sometimes she'll drain it while I'm in my chair. That's really the extent of it, just drain when full.</p> <p>That's mostly the domain of my nurse. I have a nurse that comes in for that. She inserts the suppository. She does the digital stimulation to kind of bring down everything the suppository misses. But it's usually like all one big round and then my whole bowel is clear. And she can tell and she'll be like, "Okay, you're done."</p> <p>Emptiness – she can feel it.</p>	<p>She brings me coffee.</p>	<p>Yeah, that's it. I have a bedsore that I'm also working on healing up, so the nurse probably will also be helping with that in the next couple weeks.</p>
<b>UM-020</b> Female White 52/17ysi Vehicular Comp Tetra Other Caregiver  QOL: 9.5  IC Self DigStim	NO REFERENCE	They 100% assist.	NO REFERENCE	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-021</b> Female White 55/1ysi Medical Incomp Para Other priv Caregiver  QOL: 9.5  Suprapubic DigEvac, Fiber	NO REFERENCE	Yeah, I really don't have any, my husband, I guess. But he'll come in and make sure everything is lined up where I want it.  He makes it easier, I guess, by helping me. He comes down and unhooks my urine bag, the night bag. Can I plug my short one off, and then unhook, and then hold onto it? Yeah. Could I get into the wheelchair, and take it into the bathroom and drain it myself? Yeah. He does that every morning. I can get dressed. I can shower now. But he'll come in and make sure everything is lined up where I want it.	...at the end of the day when I transfer from the wheelchair onto the bed, I'm sitting there and I'm trying to drag my legs into the bed... that's the hardest thing but he does it for me.  We put dishes down low. He put some of the food things...there's always something I could eat if nobody is here...  Everything he does, if I had to, I could do it. It would take me much longer and I was sap me of my energy part. So by him helping me do some of these things, it just makes my life so much easier.	NO REFERENCE
<b>UM-030</b> Female White 45/1ysi Fall Incomp Para Medicaid Caregiver  QOL: 5  IC Other DigStim, Lax/Meds	NO REFERENCE	He cathes me. And he'll help me do a [ditch stem 0:29:26] if I need it, but he lets me try to go by myself before I do it and I will call him and tell him, "You know what, let's try this," because I don't want to be on that commode too long because it hurts your butt.	Because at the beginning he just didn't know how, at least it was so overwhelming, you know, cleaning the house, making sure the house stays clean especially for both of us having HIV, you know, we need to make sure we're -- the downstairs is ours, you know, we need to make sure we're keeping everything clean.	Yes. And in the hospital they said no more than 20 minutes on it for bed sores and stuff.  Because at the beginning he just didn't know how, at least it was so overwhelming, you know, cleaning the house, making sure the house stays clean especially for both of us having HIV, you know, we need to make sure we're -- the downstairs is ours, you know, we need to make sure we're keeping everything clean.

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-038</b> Female White 36/1ysi Vehicular Comp Para Auto NF Caregiver  QOL: 5  IC Other DigStim, DigEvac, Suppos, Lax/Meds	Nope. I worry that my insurance company isn't going to fix my house or paying them to take care of me because right now they haven't got paid nothing.  No and he hasn't gotten paid since September.  The insurance company is supposed to do that, but they haven't even started it.	Water, drink a lot of water, I'm drinking that.  I take care of my stuff in the living room.  I brush my teeth, wash in here.  I do it all in here. He give me a bath, we can't go in the bathroom.  Yeah we wash up in the bed.	Yeah all he does is stimulate me and cath me	NO REFERENCE
<b>UM-040</b> Male White 61/1ysi Fall Comp Para Other Priv Caregiver  QOL: 7  IC Self Suppos	NO REFERENCE	NO REFERENCE	NO REFERENCE	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>UM-043</b> Male White 33/1ysi Sports Incomp Tetra Other Priv Caregiver  QOL: 6.5  Suprapubic DigStim, DigEvac, Suppos	NO REFERENCE	<p>The person that comes in and does the bowel routine and everything, really is just the same as being in the hospital. I don't find it uncomfortable in any way. Just because it is the same as what I'm used to.</p> <p>Yeah, I do a suppository and wait about a half an hour and then do some good stim and then wait a little bit longer and kind of let it do its own thing.</p> <p>Yeah, I do it in bed. I tried the bedside commode. I've tried that and it usually just takes too long, and you end up sitting there for an hour and a half and it's just not feasible at that point.</p>	<p>The help is good. They come in and they do the bed baths and the dressing and help me get in my chair every day, every morning. And then my parents help me get back into bed at night, so they don't have to come back at night, which a lot of people do. So I feel lucky that I have my parents to help me get back into bed.</p>	NO REFERENCE
<b>UM-044</b> Female White 27/1ysi Medical Incomp Tetra Other priv Caregiver  QOL: 7.5  IC Other DigStim, DigEvac, Suppos	NO REFERENCE	<p>...it's pretty much both of us saying like okay, you know I got to be – or else if she forgets I'll say, "Okay, we have to cath at this time." Most of the time she remembers but I mean it's like a teamwork you know but she caths me, does the bowel program. She's with me all day long. She basically does everything so –</p> <p>I was a very modest person before... and now I'm you know, back with my mom where she's cathing me, giving me bowel programs... I mean there are no secrets between us now.</p>	<p>Well, I mean I call her mom so – [laughs]</p> <p>I'm glad it's her and not somebody else, like a stranger but then it – other days where you know, where you're just you know, bickering back and forth. I'd rather have a stranger around like oh, they don't even care about me. Like they wouldn't look at me like that where – so it's different. We spend a lot of time together.</p> <p>Like she would literally do anything for me. Like she picks the shit out of my ass. Like you know that's deep love I guess. I don't know.</p>	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>VA-002</b> Male White 45/20ysi Vehicular Incomp Tetra VA Caregiver  QOL: 8.5  IC Self DigStim, DigEvac	NO REFERENCE	<p>I do digital stim and wear obviously gloves and lubricant, pull it out and throw it in the garbage bag and clean up.</p> <p>...with me I only have use of one hand. So I had to figure out, well I can put the gloves on like this and I can take the gloves off like this, without having to have her do it for me. If I put the garbage right here, I can reach in and put everything right there, I don't have to...so it was incremental. I mean you learn, I can do this piece on my own, ok well how do I figure out how to do the next piece on my own?</p>	<p>She does all the errands, she does all the house stuff, that I can't or don't want to do. She does the lawn and stuff like that now... she changes the light bulbs and all the stuff that I can't get up to do.</p> <p>Now if for some reason I have a loose, loose stool where it's rather messy, she will come in and help me and make sure I don't spread it over the rest of the house. Yeah, if I need her she comes in and helps out with that stuff, but for the most part, on the average day, she does not get involved.</p>	NO REFERENCE
<b>VA-003</b> Male White 35/13ysi Vehicular Comp Tetra VA Caregiver QOL: 8.5 Urinary Diversion/Ostomy Suppos	NO REFERENCE	<p>I do. I have an aide that comes in every morning for the most part.</p> <p>She comes in the evenings probably 3 or 4 times a week.</p> <p>She's there maybe an hour or an hour and a half.</p> <p>She hooks up the leg bag in the morning. That's about it.</p> <p>Usually my wife has that done before she gets there.</p>	NO REFERENCE	NO REFERENCE



Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>VA-004</b> Male White 43/10ysi Sports Comp Para VA No caregiver  QOL: 9  IC Self DigStim, DigEvac, Suppos	<p>I tried to get a standing wheelchair... I found out that I was unable to get it... But I do qualify for getting a standing frame but when I approached the people here about getting it, no one really knew how to do it.</p> <p>Basically what I think it is, is the Ann Arbor VA is not really set up for spinal cord injury people.</p> <p>The biggest thing that I've found is that if I don't get I want or what I feel I need, it's either that I don't really need it or I just need to explain myself a little bit better. Maybe do a little more research and like I said, educate them on what I need.</p>	NO REFERENCE	NO REFERENCE	NO REFERENCE
<b>VA-011</b> Male Black 48/16ysi Vehicular Incomp Tetra Auto NF Caregiver  QOL: 9.5  IC Self DigStim, DigEvac, Suppos	NO REFERENCE	<p>I do my own bladder, but again I tell you the bowel routine, part of the source of my frustration with it is the dependence on someone else, even though it's my wife. I would rather her not have to do that. So recently I'm experimenting with just doing it all myself to see.</p> <p>And obviously you could call someone in and show them your routine and things of that nature. But again, you're dependent on them coming through to do what they need to do. So again, that's a source of frustration for me.</p>	<p>My wife does it. As far as my bowel program and she will help me get dressed but that's it.</p> <p>She doesn't certainly feel comfortable with me being home by myself, particularly doing the bowel program thing independently. So we're kind of dealing with that and seeing if that's something I can do independently or if we need to bring someone else in to do that part for me, to help me with that part.</p>	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>VA-013</b> Male White 56/37ysi Fall Incomp Tetra VA Caregiver  QOL: 8.5  Suprapubic DigStim, Lax/Meds	[Regarding his job] No. I would just come and go (to deal with accidents). I was, we were on a flex schedule so you could come any time up to 9 o'clock as long as you got your eight hours in.  I would go and come back. Sometimes they didn't know I was gone. It was kind of nice.	Yeah they change my catheter, fix my bags, they'll swap the bags out between bed bags and leg bags.  The whole, yeah. So they do the manual stimulation to evacuate the bowels and make sure we're done and clean it up.  Sometimes earlier caregivers didn't get it all, didn't get it right, didn't get me done, especially in the morning on the way to work. If it wasn't done I'd have problems, have accidents.	Now I just have the one. She wanted to do everything. She wanted to take over. I had somebody on the weekends. The weekend lady would do the night time and this lady would do the morning time, but then she got a job somewhere else so she could only come in on the weekends and the other girl took over morning and night. So the other one says well, she's got a live-in position so she quit the weekends. So now she does everything.	NO REFERENCE
<b>VA-015</b> Male White 67/13ysi Vehicular Incomp Tetra VA Caregiver  QOL: 5  Transurethral DigStim, DigEvac, Suppos	NO REFERENCE	She does everything.	Yeah, well she doesn't change the catheter. [Organization] comes in once a month and changes that. But everything else, she fixes all my meals, does my laundry, takes care of the house, I don't know, she's there.	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>VA-018</b> Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver  QOL: 7  Urinary Diversion/Ostomy DigStim, DigEvac, Suppos, Lax/Meds	NO REFERENCE	Oh, she just does my bowel care for me and if I have an accident she will clean me up and all that good stuff, but otherwise it's just normal three times a week. But then, like you said, you never know. It could be 5 times a week or 7 times a week. It all depends.	NO REFERENCE	That's just in the later stages you know, because after using suppositories for 20 plus years your muscles and your, they weaken your muscles. So you don't have the same control, you don't have any control to begin with. Like a normal person can hold it in when he's got to go to the bathroom, but when you're injured like this you have no control. So when you have to go to the bathroom, you go. There's no, and a lot of times, a lot of guys can't tell, but I can.
<b>VA-026</b> Male White 64/45ysi Vehicular Comp Para VA No caregiver  QOL: 9  IC Self DigStim	NO REFERENCE	Yeah, but they don't do anything like that for me.	Shopping, house cleaning.	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Complications
<b>VA-027</b> Male Hispanic 72/29ysi Fall Incomp Tetra Medicare Caregiver  QOL: 4.5  IC Other Colostomy, Lax/Meds	NO REFERENCE	Well she's the one that does it most of the time at home. But once the aides leave, they're not back until the following morning to bathe me, shave me, and dress me and all that.	NO REFERENCE	No, because I was always, I hated to go out in case of an accident you know? Especially if it was going to be a long trip.
<b>VA-035</b> Male Black 62/28ysi Violence Comp Para VA Caregiver  QOL: 10  IC Self Colostomy	NO REFERENCE	Yeah I have a caregiver that comes Monday, Wednesday, and Friday. She works from 11:30 to 2:30, just 3 hours.  No, I do that myself. She just helps me around the house with cooking, cleaning, and washing, making up my bed. She helps me get in the shower and stuff like that.	No, I do that myself. She just helps me around the house with cooking, cleaning, and washing, making up my bed. She helps me get in the shower and stuff like that.	NO REFERENCE

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-008</b> Female White 63/22ysi Fall Comp Para Private No caregiver  QOL: 7.5  IC Self DigStim, DigEvac	NO REFERENCE	NO REFERENCE	NO REFERENCE
<b>UM-010</b> Male White 35/16ysi Violence Comp Para Medicare No caregiver  QOL: 6  IC Self DigStim, Suppos, Othr Flush	NO REFERENCE	NO REFERENCE	NO REFERENCE

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-012</b> Male White 56/12ysi Vehicular Comp Tetra Auto NF Caregiver  QOL: 5.5  IC Self, IC Other DigStim, DigEvac, Suppos, Lax/Meds	<p>We've developed internally where someone needs to be off; the other one will fill in. We've developed our own backups. Even the agencies don't bother us anymore.</p> <p>My wife is one of my caregivers and she primarily will back them up if need be, and especially again around the holidays. You know, you want them to have time with their family and what not. And so many times she'll fill in around the holidays or if just something comes up she'll fill in. So my wife can do anything they can do and in many cases my wife has taught them because she lived with me right there in Ann Arbor for the three months that I was there and learned everything of the nurses. So she can actually teach the aides, my aides, and she did.</p>	NO REFERENCE	<p>And I've had a few others but they didn't last. The ones that I have now, they've in most cases been with me over ten years. One has been with me for the full length of my injury, will be 13 years. She's been with me for 13 years. The others, over ten and pushing ten. We've become family, you know?</p> <p>We've developed internally where someone needs to be off; the other one will fill in. We've developed our own backups. Even the agencies don't bother us anymore. I mean, I work through an agency. One works for me personally and was working for an agency but it became too much of a pain the butt for her and they're the type of people that I can count on. I don't have to worry if they're going to be here. They're going to be there.</p>
<b>UM-014</b> Male White 64/41ysi Violence Comp Tetra Other Private Caregiver QOL: 9 IC Other, Transurethral DigStim, Mini- enema	<p>They need more experience in how to handle different kinds of wheelchairs. Of course, once they get the experience it's not bad. The first time around it gets rough. It's very difficult.</p> <p>A lot. I have 24-hour care and the nurses move around a lot. I've had one nurse work for me for nine years. Several others have worked for me for four years. Some of them worked for me for three months. They get an attitude with me. I don't think it's right for them to show that much of an attitude.</p> <p>Sometimes it gets ugly. I confront them first and if they don't, if they still want to argue with me then I go to the agency. And if they still want to argue with me I just tell the agency they've got to go.</p>	NO REFERENCE	<p>I had one girl come in a while back. She wanted to introduce me to her family and so on. Wanted to be my best friend. Told me all about her sex life and then wanted to know mine. I didn't say very much but she turned it around and stabbed me in the back with it.</p> <p>After having someone there that long they do become family. Even after two or three years, if you've got a friendship there that's one thing. If they don't want to do their job, I've had a lot of them come in "Oh, this would be a great job. A quadriplegic, can't go nowhere. We can sit and watch soap operas all afternoon." No, we're not. I do not watch soap operas. I am active. I get out and do things. That's how I stay away from depression.</p>

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-018</b> Male Hispanic 30/10ysi Sports Incomp Tetra Medicare Caregiver  QOL: 4  Transurethral DigStim, Suppos	<p>Well, there was a time when I was working with an agency called [Redacted Name] and they are just absolutely terrible. They would change nurses on me every week, sometimes like twice a week and they'd be barely competent. And a lot of times their only experience would be working with elderly people in nursing homes. And I had to yell at them a lot, like a lot a lot.</p> <p>Pretty much with every aide that I've had that I've worked with long term has always been someone I've wanted to work with for long term. I won't tolerate someone that I find incompetent... I mean I understand that any relationship like that you have to go through the growing pains at first, but if they haven't figured it out in a couple of weeks then usually that's a sign for me to cut bait.</p>	<p>I mean I stay at home, but at least I use the internet to keep me, you know, remotely social. Most of my friends have moved away from Michigan anyway, so...</p> <p>Yeah, there's a home theater PC under each TV in my house and they all connect to a hub in my office that has about four terabytes of storage on it. So I've got about 150 TV shows and maybe about 400 films. What I'll have to do sometimes is I'll pull up... At night I like to have the TV on because I can't really sleep without it and I'll just put it on <i>The Simpsons</i> on random and just hit play.</p>	<p>Yeah, she's due (childbirth) this weekend. Still, she transfers me. I don't know why. But she likes the job I guess and she wants to come back as soon as possible. I guess I'm not as terrible as other people in my condition.</p> <p>You just have to meet the people and talk to them and get a sense of who they are and if they can handle hanging out with me, because a lot of the time it's just downtime, hanging out and watching TV. I've got a really extensive media library that I have running to two computers by HDV in my house. I'm really proud of it.</p>
<b>UM-020</b> Female White 52/17ysi Vehicular Comp Tetra Other Caregiver  QOL: 9.5  IC Self DigStim	<p>Over the 15 years, 95% of the nurses have been absolutely fabulous—trustworthy, hardworking, honest, have integrity. I manage my own nursing case, so I hire them. That has made a huge difference.</p>	<p>It's all about adjustment. It's funny because when I was first year post injury, we were not allowed to use the word <i>catheterization</i>. We called it <i>the C thing</i>. I was just really embarrassed. I didn't want anybody to know so it was something that I kept very hidden and very private. 15 years post injury it's something that I'm comfortable discussing... It's not something that I hide. I actually even oftentimes present to other classes like the physical therapy students and I talk about it. So it's not something that I'm at all embarrassed about or ashamed about. It's just part of the process of having a spinal cord injury and I think it's really important that people understand how people with spinal cord have to manage their bowel and bladder...</p>	<p>I call them nurses just because it's a level of respect. It's an added degree, so a level of education that they've earned. I feel like that's their title and that's how they should be referred to.</p> <p>Over the 15 years, 95% of the nurses have been absolutely fabulous—trustworthy, hardworking, honest, have integrity. I manage my own nursing case, so I hire them. That has made a huge difference.</p>

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-021</b> Female White 55/1ysi Medical Incomp Para Other priv Caregiver  QOL: 9.5  Suprapubic DigEvac, Fiber	Probably the hardest thing is at the end of the day when I transfer from the wheelchair onto the bed, I'm sitting there and I'm trying to drag my legs into the bed. At the end of the day, that's the hardest thing but he does it for me. It's just, can I do it? Yeah. He's gone. He went to play tennis with my son. He's off school. I can get in the wheelchair and if I want to get back and lay in bed, I can lay there. I can usually grab one leg, then I kind of flip over and I raffle around until I can finally get my other leg up. That's probably the hardest thing is getting my legs up into the bed. I can stretch, and move them and get them out but getting into the bed is the hardest.	NO REFERENCE	NO REFERENCE
<b>UM-030</b> Female White 45/1ysi Fall Incomp Para Medicaid Caregiver  QOL: 5  IC Other DigStim, Lax/Meds	NO REFERENCE	I would get upset because... I've got all this stuff to do and I got to work 40 hours a week and it's hard to keep a house and take care of all these people that don't want to -- and I'm such a caring person I'll just do it, you know, I don't ask them. I just do it and it won't even bother me, but deep down in me yeah, it's very stressful, and I can see it in him. But other than that he's pretty good. He's gotten better since he's gotten now -- he's learned that we have to do a routine, so he gets -- at first he was kind of mean, you know? He was mean and I told him, I said, "You need to calm down because this is my body," you know. And anytime you throw my leg it's going to spas. You need to be careful, you know. We went through our times at the beginning. But now it's kind of leveled off and he understands.	Sometimes it's funny because he's even told me, he goes, "[Redacted Proper Name], I know how you felt." You know, I said, "Now, now you understand why I get gripey," you know and he's like, "I understand" ...  He understands why because I talk to him and let him know, you know, how I feel and I'm there for him to talk to me, let me know how he feels.  He needs to talk just as much and that's why I said, "You need to talk and let this out because you're holding it and you're taking it out on me." He goes, "I don't mean to," I said, "I know you don't mean to, but you need to realize what you're doing." So it's calmed down a lot.



Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-038</b> Female White 36/1ysi Vehicular Comp Para Auto NF Caregiver  QOL: 5  IC Other DigStim, DigEvac, Suppos, Lax/Meds	NO REFERENCE	NO REFERENCE	NO REFERENCE
<b>UM-040</b> Male White 61/1ysi Fall Comp Para Other Priv Caregiver  QOL: 7  IC Self Suppos	I'm totally satisfied with everybody here.  Yep, they're all doing their jobs and none of them are griping and they're more than willing to help me out with anything I need. If I need something from my room that's out of reach, they'll come and get it for me with no problem.	NO REFERENCE	Yep, they're all doing their jobs and none of them are griping and they're more than willing to help me out with anything I need. If I need something from my room that's out of reach, they'll come and get it for me with no problem.

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>UM-043</b> Male White 33/1ysi Sports Incomp Tetra Other Priv Caregiver  QOL: 6.5  Suprapubic DigStim, DigEvac, Suppos	This is new so it's going to be a couple people. There's one normal person and someone else on standby.	No. It's always been new people in the hospital. There's so many different nurses and they always have substitute nurses coming in. It used to be someone new every day, even in the hospital. Someone coming into the house and doing it, it just seems like a normal thing.	And then my parents help me get back into bed at night, so they don't have to come back at night, which a lot of people do. So I feel lucky that I have my parents to help me get back into bed.
<b>UM-044</b> Female White 27/1ysi Medical Incomp Tetra Other priv Caregiver  QOL: 7.5  IC Other DigStim, DigEvac, Suppos	No, I mean it's pretty much both of us saying like okay, you know I got to be – or else if she forgets I'll say, "Okay, we have to cath at this time." Most of the time she remembers but I mean it's like a teamwork you know but she cathes me, does the bowel program. She's with me all day long. She basically does everything so –	<p>So I mean I'm very grateful for her but at the same time, it's your mom. I mean how long can you – you can't be with your mom every single second of the day. It's like we get on each other's nerves so –</p> <p>She – I mean she's great. I have no complaints. She does everything for me. She's you know, giving – not giving up her job. I think she's retiring or whatever but I mean essentially, she's giving up her life because she can't go away for the weekend because I need taken care of. So I mean I'm very grateful for her but at the same time, it's your mom. I mean how long can you – you can't be with your mom every single second of the day. It's like we get on each other's nerves so –</p>	<p>I mean there are no secrets between us now. You know she knows everything. She sees everything. There's – but she's my mom.</p> <p>But for the most part, I would say our relationship's gotten closer just because we're together all day.</p> <p>Yeah, I mean she's my mom. I mean it's amazing what I see that she does for me now. You know they always say like, "Oh, you'll appreciate this when you're a mother and this kind of thing." Well, I'm not a mother but now I can see how much she – I mean not that I didn't know before but now I truly understand. Like she would literally do anything for me. Like she picks the shit out of my ass. Like you know that's deep love I guess. I don't know.</p>

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>VA-002</b> Male White 45/20ysi Vehicular Incomp Tetra VA Caregiver  QOL: 8.5  IC Self DigStim, DigEvac	<p>Not anymore, initially she would help me out until I developed strategies or figured out how to do it on my own, but that's been I don't even know how many years now. Same with the bowel program, when I first started, she'd be there helping me, and then I figured out strategies so I could do it independently.</p> <p>Yeah, it was important for me, and also I think it was important for her because it's, for both of us really. Especially now because I have to get up at like 4:30 to go to work, she definitely doesn't want to get up at 4:30.</p>	NO REFERENCE	NO REFERENCE
<b>VA-003</b> Male White 35/13ysi Vehicular Comp Tetra VA Caregiver QOL: 8.5 Urinary Diversion/Ostomy Suppos	<p>I've gone through a few caregivers but for the most part I've had the same two or three for the last 5 or 6 years.</p> <p>Well some were just younger and they were working their way through to whatever so they've moved on and whatnot.</p>	NO REFERENCE	<p>Once you get in with a caregiver that's into the job it's really not a big deal. If you have a couple people you can count on, your problems are pretty much over with that.</p> <p>No, I've developed friendships with some of them.</p> <p>Yeah, you're not going to go out and party with them right after that.</p> <p>Yeah after about 2 or 3 months you get to know a person pretty well.</p>

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>VA-004</b> Male White 43/10ysi Sports Comp Para VA No caregiver  QOL: 9  IC Self DigStim, DigEvac, Suppos	Yeah, yeah I'm satisfied with it. The biggest thing that I've found is that if I don't get I want or what I feel I need, it's either that I don't really need it or I just need to explain myself a little bit better. Maybe do a little more research and like I said, educate them on what I need.	NO REFERENCE	NO REFERENCE
<b>VA-011</b> Male Black 48/16ysi Vehicular Incomp Tetra Auto NF Caregiver  QOL: 9.5  IC Self DigStim, DigEvac, Suppos	<p>If I know I'm staying home or whatever, experimenting with doing the program myself to see if I, what the experience is in terms of not have someone check me after. Am I having any problems? What's going on?</p> <p>And obviously you could call someone in and show them your routine and things of that nature. But again, you're dependent on them coming through to do what they need to do. So again, that's a source of frustration for me. So we're dealing with that right now.</p>	It is, you know. It is to some degree. It's just a humbling experience. I think that's the word that continues to come to mind, because no matter how close we with our spouses when you're able bodied your time in the bathroom is your private time. It's what you do. Some people are comfortable enough with walking in or out or whatever, but nobody is in there helping you. So it's not normal. I mean it's normal for me now. So it's a humbling experience because you do lose that independence. You do lose that privacy that you normally would have. And having to have someone who you love and you live with, it's comforting and also a bit discomfoting too. Because honestly you want to make sure they still love you and understand that this is a part of your life. So it can be difficult.	And I believe part of that transition, dealing with me from that perspective was probably very difficult to deal with and handle, which in part led to our separation and divorce. So it's tough. I think that peer support, counseling with the caregiver, particularly if it's a wife or a spouse or significant other or whatever is important, because there are psychological adjustments that have to be made by those individuals too and that can't be taken lightly.

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>VA-013</b> Male White 56/37ysi Fall Incomp Tetra VA Caregiver  QOL: 8.5  Suprapubic DigStim, Lax/Meds	<p>I'd call them up and hopefully get a hold of them and say listen we've got a problem. We got to come back and clean me up.</p> <p>I would have my caregivers trained. If somebody is leaving they'd stay and train the next person. And then I was always there to guide them if they needed guidance.</p> <p>Sometimes earlier caregivers didn't get it all, didn't get it right, didn't get me done, especially in the morning on the way to work. If it wasn't done I'd have problems, have accidents.</p>	NO REFERENCE	<p>...the caregiver I got now has been with me for fifteen years... No, she's not 24 hours but we've developed that relationship where now we're boyfriend-girlfriend.</p> <p>Well, a caregiver is somebody who really cares for you and after a while I'm sure that there's some type of feelings that develop because you're caring for a person and you're doing some really intimate care. Bowel and bladder takes a certain special person to do that for somebody else. You almost have to care for them to be doing it.</p> <p>Well that and you spend a lot of time together. Spend a lot of time together and you know, one thing leads to another.</p>
<b>VA-015</b> Male White 67/13ysi Vehicular Incomp Tetra VA Caregiver  QOL: 5  Transurethral DigStim, DigEvac, Suppos	<p>Anyway to make a long story short, [Redacted Proper Name 00:31:24] said, "You're not going to no damn nursing home." And I said, "Well ok, where are we going?" She said, "I don't know. We may go to a motel." So I'm thinking a motel, we will probably be there a week or 10 days and we'll find something we can rent. It was a whole month before we found anything to rent. Now they've got kids upstairs that don't go to bed until the wee hours of the morning. But [Redacted Proper Name 00:32:15] is a fine lady, love her to death. You just don't find any better caregivers than her when she's not being a woman.</p>	NO REFERENCE	<p>That's what I'm saying, when I came up here I didn't even know her. I knew her mother but I didn't know her. And when I said I was going to live in a nursing home and she said no you're not, that made me feel good that there's somebody there. Because I've got three boys, I've got one in Tennessee, I've got one in Blissfield, Michigan, and I've got one in New Mexico. They're thinned out and the one that's living closest to me is the brokest one.</p>

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>VA-018</b> Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver  QOL: 7  Urinary Diversion/Ostomy DigStim, DigEvac, Suppos, Lax/Meds	No. Even when I have a stranger come in, every now and then a nurse practitioner or a nurse's aide, when they want to go somewhere, there's no, it's just something that's got to be done. I have no problem telling them what to do or how to do it.	NO REFERENCE	No, no she lives with me.  No. Even when I have a stranger come in, every now and then a nurse practitioner or a nurse's aide, when they want to go somewhere, there's no, it's just something that's got to be done. I have no problem telling them what to do or how to do it.  She's my sister.  We have a great relationship.
<b>VA-026</b> Male White 64/45ysi Vehicular Comp Para VA No caregiver  QOL: 9  IC Self DigStim	NO REFERENCE	NO REFERENCE	NO REFERENCE

Subject	Managing Caregiving	Psychological Adjustment	Relationship with Caregivers
<b>VA-027</b> Male Hispanic 72/29ysi Fall Incomp Tetra Medicare Caregiver  QOL: 4.5  IC Other Colostomy, Lax/Meds	Well it's friendship because there was one caregiver, I had her for 13 years until we had to change to different agencies. Even then she came over for a while but they couldn't do any dressing or bowel care before so that's why we had to switch over to RN's. They're the ones that do the bowel care now.	NO REFERENCE	Well getting aides that really care about helping you. Once I get one that's pretty dependable I try to keep that aide coming in instead of different aides coming in all the time.  Well it's friendship because there was one caregiver, I had her for 13 years until we had to change to different agencies. Even then she came over for a while but they couldn't do any dressing or bowel care before so that's why we had to switch over to RN's. They're the ones that do the bowel care now.
<b>VA-035</b> Male Black 62/28ysi Violence Comp Para VA Caregiver  QOL: 10  IC Self Colostomy	NO REFERENCE	NO REFERENCE	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>UM-101</b>  Non-family 1 recipient Female White 45 Not married Comp Para BB Yes	NO REFERENCE	Well, with that mostly it's giving him the prunes; he does one every night. And then the night before he has a bowel and shower day, he gets three ounces of prune juice. It took us a little while to find the right regimen for him, but what we've got now works. And in the morning when I get him up before we get him on the shower chair, I give him something called [Enamese 0:08:15], it's a rectal stimulation. It's liquid that helps stimulate the canal so he can go. Then we put him on the toilet for the shower and then I do – it's kind of abdominal stimulus, but I go up one side the ascending colon and roll my hand. It helps stimulate from the outside the stool to go through his intestines. I stimulate that every 15 minutes and then we give him time to go and it works.	Usually it's anywhere from a large to an extra-large and it's pretty consistent. It's pretty much every three days we have that. And then from there we do his shower and we get him dressed and he's up and ready for the day.  I keep track of it and if it starts to get dark and has an odor or has a lot of sediment then we have a home kit that we do a test on him. If it shows positive, then we go into the doctor with a urine sample and then he usually calls in a prescription to Wal-Mart. And that's about all we do for that.	NO REFERENCE	Well occasionally, I would say at least two times a year, he'll end up with a UTI from the straight cathing. And then he ends up having to go on an antibiotic. He's already had his two for this year, but it's not very often. Other than that he doesn't have a lot of trouble.  With his urinary tract infection, we just keep an eye on it as far as we make sure he's hydrated. He drinks a lot of fluids throughout the day, so that helps.



Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>UM-102</b>  Non-family >1 recipient Female White 28 Married/SO Tetra Comp BB Yes	NO REFERENCE	Not really because she's not my first client that I've had like that. I know how to cath people; I know how to do digital stimulation. I know how to do all of that stuff because of prior clients and training that I've had. And so I guess it wasn't hard to get into a routine; it was just getting used to being in her routine because nobody has the same routine – no two clients would be exactly the same, how they want stuff done or the time of day that they want it done.	We order supplies together. It's my job to make sure her meds don't get low, to make sure she's not running out of things. That way we have new before she runs out of something. So usually she's pretty good with keeping on track of that but I'm the backup to be like, "Oh your meds are getting low. We need to order them. Your supplies are getting low. We need to order them," to make sure that she always has something all the time.	It was different cause I always worked with home health agencies so the only big difference was I didn't have to chart and document every single thing that I did there. Cause usually there's a set list of this has to be done on this day, this needs to be done on this day and it's really just going by whatever she wants. It's not following a piece of paper; it's following a human being – what she wants done, when she wants it done. There was no instructions, I guess; there was just whatever she wants to do that day, that's what we do that day. That was something I wasn't used to.	NO REFERENCE

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>UM-103</b>  Family 1 recipient Male Hispanic 56 Married/SO Tetra Incomp BB No	<p>Feelings I get mostly is I don't know what tomorrow's going to be. I mean, financially, I'm always worried, you know, financially, do I have enough money to help her get into all these programs. Because the insurance only pays for so much and they're really tough to deal with.</p> <p>And you know, we have three kids, we put two through college and we have one more, we figure to graduate this year from high school and now it's his turn to go to college and, you know, and that's the one gift we said we'd do for all our kids was pay for their college so they wouldn't come out with any debts.</p> <p>Yeah, we're dipping into our reserves for paying for everything, you know, so far. Now this is just the start of our first year, so you know, it's always, you know, plus we bought a vehicle, too, for handicap.</p>	<p>Because right now she has a super pubic in her and they're talking about removing that once she gets, completes with this program it will health date. I mean she'll still be going there, but part of the research will be done then, because that one requires her to go like I said five days a week. Once she's done, she'll be able to do the follow up like twice or three times a week. Whatever times they can work in, like, yeah, and once that's done, she'll be going to using a catheter.</p>	<p>I guess the hardest thing for me was, when this initially started being frustrated at the lack of not knowing what to do to help her. You know, what kind of programs I could find to get her, to participate in for her spinal cord.</p>	<p>Yeah, and it was just hard to find places for her to go to, to get involved and any kind of form of rehab for her spinal cord. And it's not that easy finding out that information at all.</p> <p>And you don't know who to go to to get any of that information. Which it makes it, you know, equally frustrating.</p>	<p>Let's see – she had one urinary infection once, but that was early on. She hasn't had any problems since then.</p>

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<b>UM-104</b>  Family 1 recipient Male White 48 Married/SO Tetra Incomp BB Yes	Yes, on a table that's huge. We are going to check in the options of cathing differently as far as what surgery can provide but she wants to wait until it's been a year to make sure she doesn't regain the ability to urinate without being cathed.	<p>Well yeah I mean, I would say the number one, not so much with the bowel program but the bladder. Having to deal with having to urinate has definitely affected our quality of life because as it is, I've really, we've tried to cath her in the chair and it, it's pretty much, it's hard.</p> <p>So the cathing, the need to cath, the need to be home to cath or at least be able to get on a table somewhere has severely limited us into doing much. And yes she can wear a diaper per say but you know there's, that's another quality of life thing on her and, and a, and the what do I want to say? Pride you know, of being able to take care of yourself and it's just yeah you know?</p> <p>The bowel program is pretty well set. She has for the most part regular bowel movements.</p>	I stay on top of it but it, but again it's in the back of my mind to stay on top of it, to not let it go too far. But I have to as far as the bowel program, like I said have to do a dig stim once in a while which like I said, I happily do as a spouse but it's not pleasant. I mean it's not something that's, that I have, you know that's fun in any way shape or form for her or me. I can't imagine you know, I can't imagine somebody having to do it to me, but I do it. So, yep.	Which I totally agree with her, I would never force her into doing anything that she doesn't wanna do.	She's had a few minor UTI's which have trans, she doesn't feel much pain with it. I mean these were based on lab tests for UA's and, but the frequency increases, the volume can be a scant sometimes or slightly more than scant so we. I know the indicators of a UTI and we would have to, I'd have to go get a sample cup from the local hospital and then get her cathed, run that sample back up to the hospital to get the tests ran on it. That's the worst that's happened with the bladder.

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>UM-106</b>  Non-family >1 recipient Female White 21 Not married All levels BB Yes	NO REFERENCE	<p>...depending on the client, some people have to be straight cathed which is where you take – it's called a red robin. It's a little very small tube, rubber tube, that you put into your – it's a female, their urethra just located inside of her vagina and it forces them to pee out of the tube into a bag... you have to do that every two hours to make sure that they don't pee on themselves...</p> <p>And bowel, there's a couple different things people either do. They either get a colostomy bag [or]... most of my clients, almost all of them did do a bowel program... you had to give them a suppository and an enema which are stool softeners... And then after you give them that, you turn them on their side and you wait about half hours, forty-five minutes or so and then you have to go in and do a digital stim... digitally with your finger, you give them stimulation which forces them to go to the bathroom.</p>	<p>It's not hard to do. I mean, picking them up and lifting them and transferring them is a little hard, but it really, honestly is like you're a social worker.</p> <p>You're running and making sure he has water and you're running and making sure he's drinking and you're running and making sure he's eating. So if the only thing he'll eat is chicken noodle soup, you go and get chicken noodle soup no matter where – no matter how far you got to go to get it.</p> <p>It's your job. You're there. You have to make sure that they're eating. You have to make sure that they're not going to lose weight while they're sick. That's all – that's not on them, that's on you.</p> <p>...the most stressful part is a) knowing that you have someone's life in your hands constantly and just putting up with their stuff. I mean you'll go through – as a caregiver, you go through a lot.</p>	<p>You're aware of their routine like you learn – after you've worked with them for so long, you know when they have to go to the bathroom.</p> <p>...you have to really be dedicated if you're going to – if they choose not to get a supra pubic catheter or an indwelling catheter of some sort, you have to cath it every two hours. It's very important.</p> <p>There are really, I mean – the hardest part is making sure it gets done every two hours, you know, getting them back in bed or transferring them but trying to cath them in their chair or whatever. You know, if you're out and about, you've got to do it where, you know, sometimes you have to cath them in their van.</p> <p>...you have to have a special soul to do this job and a strong stomach.</p>	NO REFERENCE

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<b>UM-107</b>  Non-family 1 recipient Female White 38 Not married Tetra Incomp BB Yes	NO REFERENCE	She actually gets Botox for her bladder. She gets Botox treatments to help meet the neurogenic part of it. She gets those every eight months I think is her schedule. This last she got one, she probably just gone about a month ago. And as it was getting to the eight months, I was like, I almost think you need to up your appointment, maybe to seven months, cause it was getting to the point where she was peeing every hour. She wasn't able to hold it or was having lots of accidents. She has LOTS of urinary tract infections.	Her supplies come automatically. Her meds, you have to administer them. She has like a schedule of when she gets what meds. Once a week, they need to be, she has like one of those weekly planner, one for the day and one for the night, those pill boxes. And so once a week, you have to go through and follow her list and put what meds go in which box. She doesn't have any special diet that goes for her bowel or bladder. Sometimes, a lot of times, you have to change sheets or her pads that she lays on oftentimes that has gotten wet from leakage or flat out, just urinating that - and you have to change that through the night.	NO REFERENCE	When she has them (UTIs), she can get very red and irritated in that area. She, so then you know my solution is you use baby wipes. But my solution is to use a warm wet washcloth and not the baby wipes, because I think that just adds to the irritation. With the urinary tract infections comes tons of frequency that when, if you were to normally cath her, she would be anywhere between 400-700 mls, but during, when she has a UTI, she feels she needs to be cath'd, and you might only get 100-200. It's so frequent.

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<b>UM-108</b>  Family 1 recipient Female White 56 Married/SO Tetra Comp BB Yes	You know, and I said, “I have a job that brings us an income.” I said, “Your job is to, is to do what it takes to stay healthy.”	<p>Those antibiotics invariably mess up his bowel program because his, the stool consistency is all over the board... And, and it makes him not feel good, the medicine, actually the combination of the medicine and what’s happening with his bowel program.</p> <p>The bladder does, the bladder management doesn’t bother me at all. Yeah, I got to admit, I do not like bowel program. I, and I try not to let [Redacted Proper Name] see that, although he knows. I, but I really, you know, that, of all the things, that’s probably the thing that if I could do without at all, I would.</p>	<p>Yeah, so and let’s see, so he was hospitalized a couple times for [prostatitis] but the last time we were able to have a pic lines put in and I could administer the, the antibiotics, you know, at home through the pic line.</p> <p>...if you look at any one task [bowel program], that would be the one that it’s not that it’s hard, it’s just that I don’t like it. And I, I just, I didn’t go into healthcare as an occupation for a reason, you know. It’s only because it’s my husband... any other task itself, nothing’s that bad, you know... it can just be the accumulation of the whole life.</p>	<p>And, and we have so many people coming and going between the aides, between, and his dad, and, and people we had to hire to do things, the house cleaners, the, you know, so, so I mean I’m the project manager at work so it was, it wasn’t something hard to take on, but I said, “I don’t feel like a home owner, I’m more like a facilities manager. I’m just managing all these people who come and go.”</p>	<p>...he has prostatitis’ now and I know that once you’ve gotten it, it’s like something that’s not going away... does well without having UTIs a lot for a number of years. Basically every time he gets an infection, it’s in the prostate.</p> <p>...he’s done really well and only had one [infections]. But it had been like maybe about four a year. He actually was hospitalized a couple times because of the severity of the infection. Because he doesn’t know he even has it until it’s bad and so it seems like it comes on sudden... because he can’t feel it, he doesn’t know it.</p> <p>...his hemorrhoids were really bad... it was a daily battle on how it was going to impact his bowel program and how, and believe it or not, how bad it was going to hurt him... He could feel it. He could feel burning... and then how much bleeding was there going to be.</p>

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<b>UM-109</b> Non-family >1 recipient Female White 45 Married/SO Tetra Incomp BB Yes	NO REFERENCE	NO REFERENCE	NO REFERENCE	NO REFERENCE	Not as far as, not as long as I have been with him. I mean, the UTI. He had a UTI. But he took antibiotics. But that is it.

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<b>UM-110</b>  Family 1 recipient Female White 52 Not married Tetra Comp BB Yes	NO REFERENCE	<p>He needed setup for cathing so that required hooking the catheter to the leg bag or the large foli bag and then he would have that in a basin of water and vinegar. And then he would just kind of rinse it off and insert it and then he was set, but he needed help with emptying the foli bags. He needed help with washing his catheters because back then you didn't get a new catheter every single time – you had to reuse them. So washing catheters, washing the bags out, emptying the bags, I would do that... But actual catheterization he was able to do.</p> <p>And then in terms of the bowel he was total assistance with that. So the aide would get him up on his commode chair, insert a suppository – or an enema, I'm sorry, an enema. And then he also required digital stimulation.</p>	NO REFENCE	NO REFENCE	<p>Well he had UTIs occasionally so he would need antibiotics and you know, increased amounts of catheterization that sometimes he needed help with. A lot of times when he had a UTI his spasms would increase. It was harder for him to cath and I might need to assist him with that. His bowels, he never really... He was pretty regular with his bowels so he never really had any constipation or anything like that that we couldn't resolve at home with oral medications or enemas and stuff, so he never needed to be hospitalized for that or medically assisted.</p> <p>He did have a kidney removed because he had a kidney tumor so he was down to one kidney, but again that didn't really phase him too much.</p>



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<b>UM-111</b>  Family 1 recipient Female White 57 Married/SO Tetra Incomp BB Yes	NO REFERENCE	<p>Bowel management, that is... We were having a little bit of a problem with that. If you don't get completely cleaned out the night before you will be having accidents the next day.</p> <p>No, no. She just went and had her bladder scanned a couple months ago... And the doctor walked in and said she has a perfect bladder.</p> <p>Yes, yes. I was very happy, very happy. The doctor walked in because I had no idea – they undress you and they put you on a table and then they start scanning. And I was so scared, and you're right in the room and they, the doctor walked in and said "Oh my God, what a beautiful bladder!" I was so happy to hear that, so happy.</p>	<p>And so she can't wash, she can only wash her arms and her neck so I have to do that but it's very hard to make sure that's clean all the time.</p> <p>We had an appointment at U of M and I went to see them and I asked them, I said "She's having accidents at therapy." At therapy they'll come over to me because I'll be in this other little part just sitting there watching her. They'll come over to me and tell me "She's had an accident, you need to change her."</p> <p>Shower time is a little bit, you know, shower day kind of wears me out a little bit. You have to get her out of the bed, put her in the lift, put her in the chair, make sure the shower chair is secure, put her in the shower, wash her. Then after a while you get into a routine – she gets out of the shower, or she's in the shower chair, I wash her. I sometimes cath her in the shower so I won't have to cath her back in bed.</p>	<p>And at first when she came home I was overwhelmed, I was just overwhelmed. I said "How am I going to do this every four hours," I mean "every six hours I have to cath her? What am I going to do when we're somewhere? Where are we going to go?" I was just overwhelmed. The cathing is not a problem. U of M taught me to cath her in a chair which that is outstanding, that's a wonderful thing. I just cath her in the chair. The bowel control, at first I was like sick, I was dry heaving and stuff but now when I do it to her we turn the TV on, she puts her hands over her ears so she can't hear and I just have the TV on...</p>	<p>I think the procedure to doing the bladder control is that you get a lot of UTIs, and the problem with UTIs is... sticking something up there constantly five times, four times a day you get a lot of UTIs. So I talked to somebody at rehab and they told me to take extra Vitamin C, to drink more water. So she takes an extra Vitamin C a day and like I said we're trying to push the water and just be clean down there</p> <p>Yeah, it's very awkward, but even if it's not... You can be extra clean and the UTIs come very, she's had, she came home with one from Heartland and never had it cleared up. So she was only home maybe two weeks and it came back and it was very bad. And when that does happen your sugar gets high and so then she did, I did notice one coming a couple of weeks ago and we got right on it.</p>

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<b>VA-101</b> Family 1 recipient Female White 44 Married/SO Tetra Comp BB Yes	I can't remember his name but he will say just bring it to me. Because we will take it to Jackson VA and they toss it every single time. So we have to come here. So that comes into play sometimes. But that's more a different level of caregiving I guess.	<p>There are two different kinds of suppositories... There's one that is the vegetable oil base and ones that are like a saline base. The vegetable oil ones are better. It's pretty quick and done, you put one in and he pretty much goes on his own... it's done in 40 minutes.</p> <p>His bowel care is quick and done. Wash him up, shower afterward and we go back to the bed... So we've got a pretty simple routine...</p> <p>So I pretty much monitor as far as symptoms go by the discoloration and the smell or odor of the urine because I can tell it more than he can. So unfortunately when you have ostomies, the urine is full of extra microorganisms.</p>	<p>Just the transferring. That gets rough. I mean he's a big guy.</p> <p>He will sit right by me because I have to help him with his water or his med time so I have to break, his bag needs to be dumped. I have to take him outside to go do that because you're not going to find a mixed bathroom in a bowling alley. So it's just easier for us to go out to the parking lot to find grass and dump the bag out... We've got a good system as far as that goes. But yeah I lose a little bit of, I need the time for me-time with that kind of stuff. That was probably the only thing that was a huge adjustment for me.</p>	<p>So yeah, I'm the one that pretty much keeps an eye on the urinary tract as far as when the odor gets bad or the color. He notices, he doesn't really get too symptomatic, that's the problem. They'll ask, are you running a fever? No. He has no real symptoms until it's so bad.</p> <p>I mean for the 9 years him and I have been together, other than his implants, he's only been hospitalized three times for two or three days and it's generally for his bladder. When his revision was done and bladder stones.</p>	<p>With most people we can run to the bathroom. Him, with spinal cord they don't always know that they have to go right now.</p> <p>...he's had bladder stones. He's had them zapped and removed a couple times. He's had a lot of recurrent UTIs he's had stoma revisions. He had two stoma revisions, one before I met him, then another one. The stones, we've dealt with that. He was actually in for a blood infection from a UTI at one point in time, it went all the way to a blood infection and then he was hospitalized.</p> <p>I mean sometimes the UTIs are a nuisance. I mean you're doing everything possible on our end and it doesn't go away, but there's nothing you can do about it.</p>

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<b>VA-102</b>  Family >1 recipient Female Black 43 Married/SO Tetra Incomp BB Yes	NO REFERENCE	<p>[Redacted Proper Name] used to void independently in the beginning and then he would get a lot of profuse sweating and feeling kind of faint or light headed... he kept getting a lot of UTI's, they found that he was having too much urine staying in. He wasn't able to void enough. So that's when he went to the cathing.</p> <p>For the most part he's able to evacuate mostly sitting on the toilet. But then say if he's sick and he has diarrhea or if he's constipated or you know, I do usually have to empty him some at the end of his program. And I also have to always make sure that the suppository has been removed because if you leave the residue from the suppository in there then you're like setting him up for a bowel accident later in the day. But if it's a difficult bowel day because of whatever, maybe he ate the wrong thing or he's feeling ill then he gets really frustrated.</p>	No and I mean for a while there I had other clients besides [Redacted Proper Name] because I had my own healthcare company, yeah, so yeah.	NO REFERENCE	<p>Yeah, yeah. He would get UTI's, excuse me, he gets UTI's occasionally. Because he voids in a urinal you can see the urine all the time, the color, the smell and so forth. So we can kind of know it is a UTI. So sometimes he will just call the primary care doctor and he says hey I have another UTI and he just provides him with antibiotics. But from what I understand for the most part if you ever test his urine it's always going to have bacteria in it because he's always using catheters or whatever. But it's just the amount, like he will start to have other symptoms where he knows he has a UTI.</p>

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<b>VA-106</b>  Family 1 recipient Female White 69 Married/SO Para Comp BB No	NO REFERENCE	Once the bowel program got really solidified pretty good with that. Early on he would, you know, it was not, we'd drive out to church and get there and then I'd say "I smell something." But that hasn't happened. That was way early on before the program got really established, I think.	NO REFERENCE	NO REFERENCE	<p>He's had, of course, UTI's.</p> <p>And they do monitor, because he did lose a kidney, they do monitor him fairly closely which is good.</p> <p>Early on fairly frequently but over the years not as frequently. Maybe, I'm just throwing out a real guess here, two times a year.</p> <p>Once the bowel program got really solidified pretty good with that. Early on he would, you know, it was not, we'd drive out to church and get there and then I'd say "I smell something." But that hasn't happened. That was way early on before the program got really established, I think.</p> <p>Not associated with the spinal cord injury, no. He has distress, his memory issues that he's now having and he's aware of.</p>

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>VA-107</b>  Non-family >1 recipient Female Black 28 Not married Para Incomp BB Yes	NO REFERENCE	<p>After he uses the restroom and everything, he has the soap in there and everything, I will go in and clean that area up and make sure that he has another tube, another straight cath and another lubrication out before I leave.</p> <p>I remember once he was telling me he was having trouble having a BM. He was constipated. The nurse came in and gave him a suppository. After that, he started to go.</p>	<p>After he uses the restroom and everything, he has the soap in there and everything, I will go in and clean that area up and make sure that he has another tube, another straight cath and another lubrication out before I leave.</p> <p>It's not difficult. I mean, it's my job.</p> <p>No. I'm still very family-oriented. I have a pretty big family. We still get together like we're supposed to. I work between the hours of nine and three. I have every other weekend available. I have the time after 3 PM to be available when everything's done. Nothing really changed. And of course I make my own hours.</p>	NO REFERENCE NO REFERENCE	I remember once he was telling me he was having trouble having a BM. He was constipated. The nurse came in and gave him a suppository. After that, he started to go.

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>VA-108</b> Family 1 recipient Female White 57 Not married Tetra Comp BB Yes	<p>We got them through the VA, but we would come really close to running out sometimes and I would hoard them. Order extras whenever I could and just keep them on a shelf in case we came to a time – sometimes we'd go two or three months when they weren't able to get them.</p> <p>Yeah, other than that, we didn't have any issues with anything else. Because of that, because we could not go through an agency and have his bowel program taken care of, we would hire people who were not through an agency or not even really aids to come in, which we ran into problems with people not showing up, things like that.</p>	<p>We started out with a twice-a-week routine and then it was breaking in between, which was very frustrating for both of us. Because he would be wet and need a bath and have to come home from work early. I would have to come home from work early in order to change it. So then we went to an every other day [condom cath?].</p> <p>Bowel management, he always used digital removal of impaction, and we just did that every other day. And it worked beautifully for 30 some years. Actually 40 some years...</p> <p>We did, to a great extent, plan our activities around it because it was an every other day thing. We would try to make sure we didn't need aids two days in a row, so that I could take care of it, so that we just didn't have to go through all the red tape and pay the extra for an RN to come in.</p>	<p>Occasionally, getting supplies was difficult because the type of [inaudible: 13:07] he had was done back in the 60s, and we never had it revised because it worked.</p> <p>I didn't have any problem with it. I've been a nurse's aid and then an occupational therapist, and so it was just kind of a matter of course for me. We did have difficulties getting aids. If we went through an agency, the aids were not allowed to do the manual removal because it was an invasive treatment. So we would have to pay for a nurse to come out to do that and we would have to get a doctor's order for it.</p> <p>That was probably the biggest hassle when I was not able to take care of him, or if I wanted to take a few days off and go do something. We had to plan around that. And I don't see any reason why aids couldn't do it, as long as they were trained.</p>	NO REFENCE	<p>And through the years, he would get a lot of urinary tract infections... So when he was on certain antibiotics it would increase the acidity of the urine and it would break more often and we would change it twice a day instead of every other day.</p> <p>And about 2010, he ended up with a kink in his bowel. And had to have surgery and then after that, we had to do a lot of stool softeners and enemas and things like that, and then it got real messy and it was no longer every other day...</p> <p>Well, at that point he no longer went back and forth to work because there were too many accidents. It was almost a daily occurrence.</p> <p>And then they found the bowel obstruction and did surgery... by the time they figured out what the obstruction was, he had not been keeping food down for probably three weeks.</p>

Subject	Access to Resources	Bladder & Bowel Management	Caregiver Roles & Responsibilities	Competency in Caregiving	Complications
<b>VA-109</b> Family 1 recipient Female White 65 Not married Tetra Comp BB Yes	<p>And so therefore, I would have to have somebody come and just to stay with him. And it would be an aid usually or something because then the VA would reimburse – well, actually they paid for it. We didn't have to pay for it. Mostly, I did his care because I liked to do his care. I don't recall that anything was really ... only in those times that he was stuck in bed and I needed to do other things, would be the only time.</p>	<p>He used a leg bag... The idea with the condom cap is that the bladder emptied constantly so that you weren't getting big rushes of urine. Because if that would happen, then the catheter couldn't contain it all and it'd come off... that would happen occasionally for whatever reason, and of course he would be horrified...</p> <p>...there were times that whatever the different evacuation method we were using – whether it was the little suppositories or when they wouldn't work – and it would be three, four hours we'd be waiting for it to work, and we'd have to do a second one and then if you'd had several days when you didn't have a bowel movement... But that was rare. Then we knew, okay, it's time to switch to some other form of tricking the bowel into knowing you have to go to the bathroom. But there were no major. Like I said, he was really lucky.</p>	<p>The times that he was stuck in bed, due to the pressure sores when he couldn't get up because he was open, those times were ... they weren't really difficult, but we had to have help. Because I couldn't leave him home by himself. I could leave him home by himself for a short period of time if he was well and in bed, but I wouldn't ever do it when he wasn't.</p>	<p>And of course [Redacted Proper Name]'s fortunate – he didn't feel the pain. His body was feeling pain. It's really funny, he wasn't taking, when he was in the hospital with that, he didn't take the morphine, Demerol, whatever they were ... and his blood pressure was going sky high and they were giving him all these medications to bring his blood pressure down. And they said, "Sir, aren't you in pain?" "No." And they said, "I think your body thinks you're in pain." Sure enough, they gave him the pain medication and down came the blood pressure. Because his body knew he was in pain even though his brain didn't.</p>	<p>But as far as same thing with bowel, you do the best you can. Occasionally there are accidents and you just come home and you deal with it, because what else can you do?</p> <p>...if I saw a red spot on his rear, he'd stay in bed and stay off of it for a day or two until it went away.</p> <p>Wound up with a pressure sore, had osteo, we were in bed for a while, and he got that all cleared up. They took him off all the antibiotics, "You're good to go." A year later the osteo came back.</p> <p>And then he had a triple A, abdominally [inaudible: 26:52] aneurism... we thought we had all this licked, but the triple A had been like two years before he died</p> <p>...he died of liver cancer and of course that's the first sign of liver cancer, is nausea and digestive issues. And of course he had all of that from this surgery.</p>

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<b>VA-110</b> Family 1 recipient Female Asian 63 Not married Para Comp BB Yes	NO REFERENCE	Exactly that. The doctor was, “Stop eating! You have to clean your bowel.” The x-ray showing so much in there. We had gone through that three or four times, and it was real difficult. One, he’s laying in the bed, everything I have to deal with. Secondly, he got a sore. And then drinking that stuff without eating, that was another battle we’d have to deal with. And I remember one time, I finally couldn’t deal anymore, so I took him to the VA. VA took him in and clean him out and send him back. I’m like, “Clean out.” He told me the guy helped him have to wear almost like a raincoat. Shower him. Everything. They got that kind of equipment, I don’t. Home is not a place to do something like that.	NO REFENCE	...in and out of hospital a lot. You know, toward the end, because his cancer he getting weaker and a lot of times we in emergency. Almost like every other week, we had to run him to the emergency. And when the hospital decided to keep him in the hospital, first thing I asked is, he needs a private room. It’s not because we want to have a special treatment, it’s because when he in the patient room, share with other patient, when he need to do bowel movement, he was very, very embarrassed... So when I do this request, I always stress, I say I’m not sure all the physician or fully understand. They just, “Okay, you want a private room. Can I give you one?”	You know, I have to say some of the medication he took toward the end, special targeted on cancer, brain cancer, lung cancer, chemotherapies or radiation have side effect. And that cause him – one thing, not wanted to eat and the second is alter his bowel movement.  Yeah. Bowel accident. So we have to rush back home. He couldn’t even tell the kids what happened. And when things like that happen, kids know. Kids knew what happened. So we had to rush back home, get cleaned up, change the clothes and then went back. By the time we got there, the concert’s almost over.



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<b>VA-115</b>  Non-family 1 recipient Female White 22 Married/SO Para Incomp BB Yes	NO REFERENCE	<p>Yeah, so with his bladder it's really in the morning just switching him over from his night bag to his leg bag and then at night vice versa. So every day while he's in the shower he straight caths himself which most of the time he needs a little help with that just because he can't see directly down to where he's trying to put the straight cath in...</p> <p>So we do that and then his bowel program we do every morning. Usually we don't have to do any extra stimulation. Usually his bowels are all right there and we have to pretty much, I hate to say dig it out for him. A lot of times once we start it all kind of, it's easier to get out.</p> <p>Everything affects it, when he's been in the hospital for something or on some medications it could make it really loose or opposite, really hard. That can make the morning a little more difficult and can throw us off schedule...</p>	NO REFENCE	<p>In the beginning when I first started working with him, it was difficult to get used to his bowel program, especially for someone who had never done it before. But even when I came back 6 months ago and I hadn't been working with him for a couple years it took me a good time to get used to the bowel program again. Even watching him straight cath himself is something new to me that he never did before but that he does now. That took a little time, just getting used to watching him do that and everything. But other than that, now I'm used to the bowel program and it just comes as second nature to me. I can sit there and have a conversation with him while it's going on and it's kind of just normal now.</p>	<p>He gets UTIs all the time. Other than that I don't think he's had any major issues. Nothing regarding bowel and nothing more than the UTIs and he gets those very often.</p> <p>No, he never asks for any help. I just know that quite often we have to help him get a urine sample or specimen then he has to take it in and it usually comes back that he's got a UTI. Usually we can tell because he gets irritated and cranky and usually that's the beginning sign of him having a UTI.</p> <p>I would say definitely. He has got rods in his back that cause him pain all the time, especially with the weather changes</p>

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<b>VA-117</b>  Non-family >1 recipient Male Black 52 Married/SO Para Incomp BB Yes	NO REFERENCE	<p>It's not difficult, the only time it becomes difficult is when he doesn't have that result. Yeah. Because that makes me feel, likewise to me if I don't go to the bathroom it affects me. But I've got a lot of things, I can exercise or things and then get my results. But this person, you sit in a wheelchair all those hours and maybe you are gassy, you know, you just feel like you need to go. The only time you can go is when someone is there with you. So if we are trying and I leave without him having a result, to be honest it affects me. Because I know how it affects a normal person. So that's the only time. Helping, cleaning, enema administration doesn't bother me. No it does not.</p>	<p>Yes, we go to church. We still go out with my family. When it's my family time, my wife and my son or my friends, I hire somebody for that day because I work two employees. I call them to relieve me whenever I need a relief.</p> <p>Yeah. So when we are going to church there is an employee that comes in and stays with one client if they don't want to go to church until we come back. If we want to go out with my wife and my son and maybe a friend, there is somebody to take care of it, so it's taken care of.</p>	<p>Yeah, sleeping in the same bed. So I approached him one day, I told him I'm kind of feeling uncomfortable doing this while your wife is there but I can't have you change because this is your house, this is your life, so I told him you know what, it's life. Let's continue doing it. We talked about it and from there it's very normal to me, I know why I'm doing that and I know why that's happening. If nobody is there to take care of him, his wife is there to take care of him. So we are all caregivers. She gives care, I give care. We are all caregivers.</p>	<p>I would say there was a major complication, there was a UTI and that was part of it. I've got a visiting nurse that comes to my house to check with the other vets. I'm surrounded by medical people. There was a time were talking and discussing the general thing because she know what I'm doing. So then it kicked into my mind, we talked about my job because she was asking me the same things about when I go to sleep and do I sleep there. Every other, every 2 hours I have to cath him, but she doesn't know him and I can't disclose anything. So then she asks why. Then I told her that's his program, that's how he wants it. But then she mentions to me, but that can cause a UTI.</p>

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<b>VA-118</b> Non-family >1 recipient Female White 22 Married/SO Tetra Incomp BB Yes	NO REFERENCE	<p>Oh, it's not too difficult besides if I have to change the Foley that's really hard because I don't have much experience doing that. And then with the sterile technique, it should really be done by a nurse or someone, but he puts enough trust in us to do it. And then keeping the condom catheter on properly because it will get twisted and then the urine will back up into the condom then it will loosen it and it will be too loose and he will have to change it. Otherwise it will come off during the night if any of the wiring is twisted and then he'll have a wet bed and they will have to change it which makes it a little harder for him in the morning and the day staff.</p>	<p>Well usually he goes on vacations during Christmas and this year he is planning not to go just because he has to be turned every 15 minutes on the plane and I'm guessing that puts a lot of stress on him and the caregivers that go. But his wife wanted him to go, but he said that he's not going this year.</p>	NO REFERENCE	NO REFERENCE

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<b>UM-101</b>  Non-family 1 recipient Female White 45 Not married Comp Para BB Yes	NO REFERENCE	NO REFERENCE	No, because [Redacted Proper Name] has been – he’s 20 years, I think last month. In October it was 20 years from his accident, so he has already went through the things that a lot of the quads go through, a lot of handicapped people go through. He already went through the depression stage and stuff like that where he was really, really depressed, but he’ll tell other people – he’s kind of a motivational speaker to other handicapped. That’s why he goes and visits them to try to let them see what he does and show them that there’s life outside of your disability. So emotional, he just gets frustrated sometimes with his wheelchair if it doesn’t work right or if something breaks on it. He gets upset with that, but as far as any emotional things connected, he’s come to terms with that many years ago.	Yeah, we are closer than we were when I first started working. He’s had a lot of nurses come in and out of there. It takes a little while for you to be there before he actually trusts that you’re going to stay and trusts that you’re going to be able to care for him the way he wants to be cared for. I would say over the length of time, the longer I’m there, the more trust I have with him and the more ease in our relationship.

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<p><b>UM-102</b></p> <p>Non-family &gt;1 recipient Female White 28 Married/SO Tetra Comp BB Yes</p>	<p>Now, because of that [extra rehab], and how hard she has worked, I mean, she is able to stand up now, stand up in a walker, and she's able to take, I don't know, I mean, it's hard to say, I mean, she can walk into our kitchen now with a walker. Granted it's not the smoothest walk you're going to see a person take, or the fastest, but the fact that she's able to do it and, of course I follow her with the wheelchair into the kitchen, but she's able to walk into the kitchen and then, you know, I'll set up the wheelchair behind her and then she sits down.</p> <p>Yeah. And you know, we've been very lucky to be finding out these programs, you know, for her to get involved in. Because up to, until she got into Ohio State, she never even stood up in a walker until she got there.</p> <p>Had her up and standing in a walk probably within two weeks. I mean, getting up from a wheelchair into a walker. So, I mean, it's just incredible to see that.</p>	<p>NO REFERENCE</p>	<p>Yeah, her family stresses her out, like her distant family but whose family doesn't?</p>	<p>No, I've worked here for five years and [Redacted Proper Name] will still explain the same things over again. So no, we don't have any communication errors cause she really has her stuff together, I will say that, cause even I cook the same meals 30 different times for her and she'll still be like, "Don't forget to add that," and I'm like, "I know, [Redacted Proper Name]. Not my first rodeo." And she's really good with over-explaining things so there are no communication errors so there is no forgetting anything. Cause if it's programmed in your brain, she'll still remind you.</p> <p>Sometimes I find it to be a little much because it's a constant reminder. I'm like, "Yes, I know," but after hearing some of her stories of some of the past workers, I'm like, "I understand why you do that."</p> <p>Nope, everything is pretty easy-going. I know what I'm doing and if I don't know what I'm doing, [Redacted Proper Name] has no problem explaining it to me. So no, there's no... not difficult at all.</p>

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<p><b>UM-103</b></p> <p>Family 1 recipient Male Hispanic 56 Married/SO Tetra Incomp BB No</p>	<p>And then from there, you know, after we eat our breakfast, she'll get back up in the walker and she'll walk into the bathroom and sit herself down on the toilet. So, she's able to do something that we thought was never going to be possible, of what she has achieved on her – you know – with all the support from everybody. Which just encourages her more to work harder and harder at this.</p> <p>Oh – okay. That's what we finally got because she's 55 and, you know, so it makes the transfers into our car pretty easy, but, you know, and this hard weather, it's, so we got into something that's going to be easy for both of us. So that's what she, you know, so we went and made the plunge and bought a van. Minivan with one of those ramps and, that's been such a, I don't know – a game changer for us, I guess. You know, makes it so much easier just to get in and out and do things.</p>	<p>My breaks are – I take time out for myself in the evening. I play tennis at night, and I usually do that about, you know, twice and sometimes three times a week and that's been really very, a stress relieve I guess for me. I guess you could say.</p> <p>Strength? Support. Moral, we're always looking out for each other, you know, more for each other, I mean, she's always looking out for me, you know, because I'm a diabetic and she's always, she's keep up on my making sure I'm taking my meds, and taking my insulin shot and that I'm going out to exercise and work out and play tennis, you know, she knows I love to do that. And she always, you know, always encourages me to do things. And the same thing with me for her.</p>	<p>She's an incredibly, incredibly strong person. Emotionally. I'm not saying she doesn't have days where, you know, she's saddened by what's happened to her, you know, I mean, that would go to anybody, for what happened.</p> <p>But, you know, emotionally I think from the both of us, we've learned to deal with it rather early instead of denying it and not accepting it. Which I think helped a lot because she has really pushed herself not accepting the doctors' prognosis about her always going to be confined to wheelchair. She's always pushed herself to rehabilitate herself as much as she can</p> <p>Yeah, and show videos of her getting up and walking in her walker. She gets a lot of letters of encouragement from everybody. Some people still at work and friends and other acquaintances that she's you know, met, of my soccer program and, so she's never really sad to the point where she's depressed because it's been a (inaudible 0:21:12) of support from everybody. I mean, you wouldn't – and it's like I said. This has really amazed us. I mean, people that's came out of the woodwork to help.</p>	<p>And we go out to restaurants, you know, now, we go to movies. We'll got to a basketball game, you know, at the colleges and out, and still out going, but, you know, but she's got to plan a lot more.</p> <p>I find myself a lot more protective of her, you know, than I ever have before, you know, and it's just, it's really weird to explain. It's not like – we never had a bad relationship. But, I mean, it really strengthened our relationship with each other. I mean, we look for each other for strength now, you know, we lean on each other a lot.</p> <p>...we're constantly helping each other, to maintain as normal a life as possible. So, I mean, so there's a lot of support for us. I mean, nothing change, well, one's more demanding than the other. It's – we want things to stay as much as normal as possible. And we encourage each other to live that way.</p>

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<b>UM-104</b> Family 1 recipient Male White 48 Married/SO Tetra Incomp BB Yes	<p>I'd, we'd tried at home I can't do it so she needs to lay down to do it. That means that unless we, we have, we can't go very far from home, simple as that. We can do it at the therapy her on Anne Arbor because there's, the tables raise and lower that can work with her chair but that has put a stop into doing any sort of travel; for whatever we want to travel for even you know to visit family or something. So we cannot be very far from our home because she needs to be cathed.</p>	<p>Not any more than normal. There's always that sense in the back of my mind when does she have to go? You know is she comfortable? Is she gonna need to cath, is she gonna feel the need to cath on our way home or? Yeah that's always on my mind and yes.</p> <p>This week for whatever reason she's having a little trouble going and it worries her, but she goes a little bit and I try to reassure her you know it's going to you know be okay. I stay on top of it but it, but again it's in the back of my mind to stay on top of it, to not let it go too far. But I have to as far as the bowel program, like I said have to do a dig stim once in a while which like I said, I happily do as a spouse but it's not pleasant. I mean it's not something that's, that I have, you know that's fun in any way shape or form for her or me. I can't imagine you know, I can't imagine somebody having to do it to me, but I do it. So, yep.</p>	<p>She, I will give her all the credit in the world. I think she is the exception. She has an extremely good attitude with this, way more, I admit way more than I could ever have. A very good positive outlook and she accepts it, she does not 99% of the time she does not get down about it. She's positive about it and she looks at it as like a lot of things in life that everything happens for a reason. I give her all the credit in the world and I think she's the, she's got to be the exception to the type of injury that she has to not be extremely down or anything like that.</p>	<p>Well I will say I, I probably value seeing her more than I used to because I realize that she was very luck that she wasn't killed... The level of care that she got from the moment of injury, from my mom calling 911 to the paramedics arriving and for her just flown from Jackson to U of M and given emergency surgery, everything, we were told that everything just went perfectly time wise and it could have turned out way worse if something didn't work out the way it did. So I do value her being with me.</p> <p>Like sexually things have obviously suffered because we can't physically do things like we used to and she misses that as well. She expresses that to me and, but I try and reassure her it's okay because you know, our love comes first before the physical aspect of it. But yeah I, I miss it but not the degree where it's hugely depressing me or anything like that. But the, the overall, I value her time more and realized that you know, it could, could've been gone in an instant. But it, but I do miss doing the things that used to make us happy and laugh and, and the times we used to do things together. Yep.</p>

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<b>UM-106</b>  Non-family >1 recipient Female White 21 Not married All levels BB Yes	<p>And sometimes if you're like shopping, they don't have big enough bathrooms to do it so you have to improvise. I mean, that's the most stressful part about bladder control bowel program...</p> <p>That irritates me to no end... they say they're handicap accessible this because they have handicap accessible that, but they don't. They don't have, you know, they have – you have to walk around the corner to get onto the sidewalk because they can't – they don't have enough area where somebody in a wheelchair can get up onto the sidewalk or then a lot of places don't even have that so you have to jump the curb. But some of your patients, they can weigh 250 pounds, 300 pounds. You got to be able to lift that wheelchair and get it on the curb which is not easy by the way.</p> <p>You know, I could sit here and rattle a list of problems they have. They don't have, you know, wide enough doors. That trying to squeeze somebody in a wheelchair through some of the doors people have are ridiculous.</p>	<p>If you do not have a strong stomach, you will not make it in this field. But for me, honestly, the hardest part about taking care of people with spinal cord injuries is their demanding nature. The bowel programs are easy. They don't bother me. Cathing someone does not bother me... honestly the physical part of the job is the easiest part of the job.</p> <p>You have to be their support group... I mean, you have no choice. That's your job. You're there, that's it. So you're there with them twenty-four hours a day... So you're like with them all the time. You become their family... So really the hardest part of the job is... the mental strain of being that person's confidant.</p> <p>I would not call it a burden because I love my job and I do it because it makes me feel like I'm doing something worth doing.</p> <p>...the most stressful thing about the job is just knowing that you can't make errors.</p> <p>...you have to take a step back and just say this is your patient, this is not your family member... even though you love them like they're family... you have to take yourself away from that aspect of the job...</p>	<p>Oh yeah, that's really all there is to it. I mean, a lot of people struggle with it because especially at first after they have their accident because it is embarrassing.</p> <p>And it's very – at first, it can be very, very – it's very humiliating for them.</p> <p>But as they go through the process and they learn how to deal with it, a lot of the time it becomes a time where you guys talk the most [bowel and bladder program].</p> <p>I mean, it's not easy to let someone come and cath you or do a bowel program on you because they're embarrassed. That's humiliating. You know, here they are 32 years old, 20 years old, and they have to have someone there to clean them up.</p> <p>That's what is stressful about this job is a) they can be very mean, they can be very, very – they can be very – they're mean. Spinal cord injuries are mean... But you constantly – have no choice but to take it. If they're yelling at you, you can't yell back.</p>	<p>You go in there and the whole time you're doing bowel program, you talk about – you know, they talk about the weather, they talk about the TV or what'd you watch last week or how work was the day before. You know, they become very comfortable with you. You just become the natural part of their day that they just have somebody there and you just do what you got to do and you – it becomes your one on one time.</p> <p>...you have to be that person that if they fall down, you have to pick them up. If they are having a bad day, you're the one to have to cheer them up. If they need advice, you're the one that they talk to. So you constantly have that thought that okay, well, I have to take care of this person.</p> <p>And because I'm with that person so much, you – I mean the slightest change, you know it instantly... because a slight change in their personalities could be they got a UTI, they have an infection, they have a huge problem.</p>



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<b>UM-107</b>  Non-family 1 recipient Female White 38 Not married Tetra Incomp BB Yes	I would say one thing would be her Hoyer lift. Those things, and part of it is that her bedroom is carpeted, and just getting her in and out of bed sometimes with that lift, trying to get that turned and get the legs properly into the bed. It's just a pain. I mean, I can do it, but it is a pain.	Just positive. It could always be worse. There's so many people that have it way worse than I. I'm lucky to be alive. I don't like what has happened to me, but it happened, and it's what life dealt me.	No. She's got a great attitude. I mean, I give her tons of credit for the attitude that she has.	No. I mean tough physically would be that. I guess the only thing is I have a tendency to emotionally feel bad for her when she's going through these UTIs and at night you're putting her to bed at 9 and she's getting up at 4:30 and as it is you have to get her up every 3 hours - not get her up, but semi-wake her up to cath her. But then she's having these UTIs and she's asking to be cath'd every 45-55 minutes.

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<b>UM-108</b>  Family 1 recipient Female White 56 Married/SO Tetra Comp BB Yes	<p>He was very adamant about getting back to work... he wanted to try and so, he was so adamant about it, you know that I mean everybody kind of banded together to, at work they, without him officially coming back, they said, "Well why don't you just come in for a week or maybe a month and just try it and see, see you know what it's going to entail." And so he did and he saw it was going to be extremely difficult... I could see all this churning in him, you know, his, you know, he wasn't going to give up and despite you know, the problems.</p>	<p>Definitely our faith. We're Christians and, and believe me, many times through this I, I mean even though praying to God all the time, I forgot to hand it over to Him and let Him, know that He's there to help me. And so I tried to it all myself. I tend to be like that too, it's like take it all on and superwoman's going to do everything, you know. And I had a couple, you know, I don't want to say near collapses, but I had a couple parts, times during it when I was at the edge, like I can't do, I can't, one more day, I can't take one more, I can't do one more thing. I can't take one more day kind of thing. But when I stop to pray and remember, "You know what, God is there to help me"... So it has been a tremendous turn around and how I personally handle it is once I just gave it over to God and said, "Okay, you know, I need your help every day and I need to do it with joy."</p> <p>We also both have large families and they, they have been a tremendous support system."</p> <p>And we believe God works through people. God touches you through people so He's used many people in our life to help us out.</p>	<p>He has fear if I'm going to be gone, I'm going to be some place. Like I, I used to, I love to travel and I used to travel. I traveled for work off and on, but not so much after his injury... But I have taken several vacations since his injury and I, you can just see the fear build up in him, like what happens if he gets sick when I'm gone?... So I know he has that anxiety... and I can tell it's because he feels like he has no control.</p> <p>I said, "Your fulltime job now is to stay healthy for this family. We need you around and that's a fulltime job." And I to this day, I tell you, even when Doctor [Redacted Proper Name] you know, his (inaudible), he is probably one of the healthiest quads that he still sees, you know. But you know still, still works out, and does what he can do to maintain you know, his strength and flexibility and health, you know, thirteen years later so he really wrapped his head around that and, and he made that his mission.</p> <p>And then, and then over time you know, slowly as he, I think gained confidence and he could take focus off himself.</p>	<p>I know when he first, early in his injury he went through the whole emotional, "Maybe I should have just died. You know, what am I going to do to this family in this condition?" and all of that. And you know, I had to reassure him that I'm not going anywhere...</p> <p>...And I had to get like real upfront and in his face when I like told him, "Your attitude is going to make or break this family." I had to like be real forceful and so it was kind of like we were like reversing roles...</p> <p>So we're both big on planning. Long, short term plans, long term plans... but suddenly, after that accident, it was amazing how neither of us could see next week, sometimes, not two days from now... And I got to say, only recently have we even gone to looking out to next year.</p> <p>As far as me, we, let's see, oh I know, we kind of laugh about this, but we say that we had gotten to a point, and this was both of us felt this way, that we were in these roles, that we used to, we no longer felt like we were like a family living in this house, but I called myself the facilitator, a facilities manager.</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>UM-109</b>  Non-family >1 recipient Female White 45 Married/SO Tetra Incomp BB Yes	NO REFERENCE	<p>To be honest with you, it's not difficult for me, only because I really try to, when I care give, I try to put myself in that situation. And so I never look at it in any other way than I do that and I treat somebody or I do things the way I would want somebody to do it for me.</p> <p>So my outlook on that is just it's not difficult. It's not difficult. I don't feel like - I go, man! Do I want to do this? Or - in a way I just feel that, I want to make it as easy as possible for him. For him. In order for him to not feel like I'm invading his privacy, his life or that he's - I don't want him to feel that he's incapable of anything.</p>	<p>Well, I think the biggest thing is, I mean he's got a very positive outlook. Very positive. And he stays pretty focused. But I think as far as he's at, if he feels that he's going to have an accident, as far as a bowel accident, he seems a little more stressed. And rightfully so.</p> <p>And it seems that it will, it kind of not - gives him the, I mean he wants to stay in. He doesn't want to go anywhere. He likes to go out. He likes to do things. He's pretty active. So that, I mean, I've noticed that that of course will prevent him from having that positive. You know, he's not as, he's more reluctant to leave the house if he feels that bloated-ness or that urge that sometimes he might get that.</p> <p>Not noticeably depressed or anything like that. But he's by no means depressed about it. Just a little more frustrated.</p>	<p>Right. Right. Just, yes. Just respecting that dignity, just preserving that dignity for somebody. I feel that's important. And even when we're out and we're out somewhere and maybe picking up lunch or anything like that. I try not to hover too much and try to give him the independence with the splints that he has and not to make him feel that there's any difference there.</p>

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<b>UM-110</b>  Family 1 recipient Female White 52 Not married Tetra Comp BB Yes	NO REFERENCE	<p>So it was the times of not being able to do that, or we'd go camping, we enjoyed camping and outdoor stuff. And it was frustrating to be at the beach and not go on the beach because of the sand and his wheelchair, or wanting to go swimming and it was difficult. Or camping, we needed to always go with somebody to get him up and out of his chair and stuff. So that was frustrating. But you know, we plunged along and did stuff, so...</p> <p>Yeah. People would tell me that I wasn't the exact same person that I used to be, and only until after the fact did I really see that in myself because it just consumes you.</p> <p>To, from being a caregiver. Or I was tired from doing everything and you know, working, being a mom, being a caregiver, doing everything – it was just hard to make that shift. And then after a while it was like well, why bother, do you know what I'm saying? So it was different.</p>	<p>I mean he had very frustrating days, you know. There were days like at some point... For the most part we had very reliable caregivers but there were times where they would come and go. And so that was a lot of burden on me because I couldn't leave him in bed for long durations. A half hour, fifteen minutes was one thing but anything longer I would have to get him up before I went to work and stuff. So that was always hard on him because he knew how much of a stress that was on me, for both of us really. So that was hard. It was frustrating when he would get frequent UTIs.</p> <p>I think he was depressed on and off. I mean he had episodes where depending on the time of year, you know, fall time was hunting season and he didn't hunt after his injury and stuff and so that was hard. Near the end he had difficulty with eating so he had dysphagia, and so he had a feeding tube and-</p>	<p>No, I think for the most part, I'd say the first ten, fifteen, years, ten years, twelve years, you know we got along, we talked it through and whatever. Near the latter part his health started declining and so there was a lot more depression, there was... The role of caregiver versus lover versus partner really was meshed and I think it was very, very difficult for both of us.</p> <p>Difficult that it was more in a caregiving role than necessarily partner and lover relationships.</p> <p>Difficult meant again, I was in a relationship where... In a relationship you usually, it's a mutual thing and there were many times where it wasn't necessarily mutual. You know, I was in that caregiving role all the time and it was just really hard to shift gears.</p>

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<b>UM-111</b>  Family 1 recipient Female White 57 Married/SO Tetra Incomp BB Yes	<p>No, she's in a wheelchair and we have a van and she wheels up the ramp and we lock her in, and we let her friends take the van.</p> <p>I know people in wheelchairs who cath themselves and do their own bowel control. They stick a suppository up there and sit in the toilet, you know. So I'm hoping someday she can do her own. I would like her to have her own independent little life as much as possible.</p>	<p>But I mean it's just, you know, I don't have any more independence, you know? Like your kids are little, I have a kid – I have a 150 lb. kid because I can't leave her alone, I can never leave alone. So I lost my independence of you know, running up to the store real quick or running to lunch with my girlfriends or whatever that might be. But I never had that because I always worked.</p> <p>At first I was a little upset because everybody, you know, it was just me and her. Her dad gets up, he's a good dad but he gets up and does his thing and goes off to work. And he's gone for 12 hours, 14 hours a day...</p> <p>Well we don't have as much independence as my husband and I did...</p> <p>I bought a, I had a mid-life crisis – a couple of years ago I had a friend pass away and I bought a Mustang so I always enjoy getting in the car and just driving my Mustang around, you know, the breeze and stuff.</p> <p>She was always grouchy but now she's, you know, she's on a little bit of antidepressant but it's helping, you know?</p>	<p>And one day when I walked into U of M she wasn't dressed and U of M always got her up, got her dressed, had her in her chair. She just wanted to lay in bed, and when I walked in she was looking out the window and she looked so sad. And that's the only day that she's ever been like that. She's had one breakdown since she's been home where she got really mad and was crying hard. We said just let her cry. She wanted to get it out, she did. But 99.9 of the times she's happy-go-lucky, you know? She has friends that come and get her and take her to lunch or they go to the show. They haven't been in the last couple weeks because they've all been busy with getting their kids to school and stuff but she has three good friends that take care of her, so, I mean that come and see her, so...</p>	<p>I mean imagine finding your daughter November 10th and now moving to a hospital, being there every day not knowing if she was going to make it – couldn't talk, on a ventilator, I mean it was just terrible. So when we got to U of M the social worker said to me "You and your husband walk in here every day like you're just a rock," because we didn't know what to expect because every day was something.</p> <p>Well, at first I was angry because I used to tell her that "If you don't take care of yourself," you know, when she would go DKA, that diabetes ketoacidosis, that's when you don't take care of yourself for so long and then you're really sick and you have to go to the hospital. The nurses would tell me "You know, she's not, something serious is going to happen to her if she doesn't take care of herself," and I would beg her and beg her.</p> <p>So you know, she's got a great personality. She's not... You know, one time when it was nice out we went to the park one day, and she – since it's an electric wheelchair so she rode around on the blacktop and I kind of walked kind of fast, you know, but...</p>

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<b>VA-101</b>  Family 1 recipient Female White 44 Married/SO Tetra Comp BB Yes	He has no trunk control at all to put him anywhere. Shower chairs, I mean he could do it that way, some people do it that way. But he prefers on his left side because that's the way gravity naturally flows through our bowel system. So his is very, it used to be bad. With this new med he's on, it's amazing, and it's a med for his gall bladder being out.	NO REFERENCE	<p>No, I think it was something that physically he felt so bad that he didn't have a lot of control over how his mood was. Because he had so much dysreflexia and his blood pressure was through the roof. He was just miserable. So everything about it was miserable. He treated everybody bad, he was crabby.</p> <p>Right, exactly. We're at our norm and I don't want to pass that norm right now.</p> <p>You're almost 15, let's see he had his injury in '02 so he's 13 years out. We have no major health issues, that's huge. Their life expectancies are not the greatest with his level of injury. No, we're healthy, let's continue to be healthy.</p>	<p>Yeah. We even built our house in the process of it all and he still, to the point where he wouldn't go out. So he stayed home pretty much all the time, so that played a little into the factor. That got a little old. I mean I understood it, but you have to still have a life. He did kind of withdraw for a long time, about a year there, where he didn't want to do anything. He was mad. But it's over, that part is over.</p> <p>When I get on him, jump on it, that's where more arguments come in. Like you need to do this for your health, that's where he gets mad. He won't tell you that, but I can tell you he does. You're not my mother kind of thing. No, but I want you to be healthy.</p> <p>A teenage girl has a lot of that natural caregiving ability. They kind of take on, they get it. And she just goes ok, see you in a bit. To this day she will say, mom do you need anything? Do you need me to dump his bag if I'm gone or something? No we're good. His son would never ask that. He has no clue. It comes into weird stuff with that but that's probably a whole other section.</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>VA-102</b> Family >1 recipient Female Black 43 Married/SO Tetra Incomp BB Yes	<p>Like when we travel sometimes the hotel will say that it's accessible, but he can barely get his chair into the bathroom that they say is accessible because of the grab bar or whatever. But then we're stuck there for five days. That causes him some stress.</p> <p>There have been times where we've travelled somewhere and he can't shower because he can't get in the bathtub. This is the way it is set up so he can't shower... But it's frustrating because he feels like embarrassed or humiliated, like I can't take a shower.</p> <p>...we have to do a better job advocating for accommodations and disability rights and getting people to raise their level of awareness that grab bar in a tiny bathroom is not accessible. There are different types of accessibility. If someone was using a walker or a cane, then this is accessible. But for a wheelchair, that's not accessible... But sometimes when you're stuck in your own frustration you don't see that. So I kind of bring it back around to [hotel manager] and say, "Hey look, this is a moment for education." And he's like "Yeah, you're right."</p>	<p>Yeah you know, socially it stops us doing some things together but it hasn't changed the dynamic of the relationship with my sisters. We have a very small family and we're just very close and we still talk on the phone. I mean life changes for all of us. When my sister was in med school and doing her residency she wasn't available as much, you know what I mean? But we keep in touch by talking, like I just got off the phone with her before I came in here. So we keep in touch by talking and staying involved in each other's lives. It's me and two sisters. I do have some other sisters and brothers but they're not as close. My mom was married twice, so I have four siblings from her first marriage and then me and my two siblings from her second marriage. And there's a larger age difference. My older siblings are approaching 60 and I'm in my 40's and my sisters are in their 30's. So there's a larger age difference.</p>	<p>He has a pretty good disposition about his disability.</p> <p>Like this is something really basic that most people do for the quality of their life and I can't do this. Whether it's showering at home or even if he was used to a bed bath that would be another thing. But he's used to being able to shower in a shower and not being able to do that and still having to pay full price for the room and everything else it's frustrating and probably as I say humiliating. Because he wants to be able to independently do stuff and then now, and showering is something that he does independently, and now in this situation I have to bathe him. And not that he's embarrassed to be around me like that but it's just like, I want to do this on my own and not have to have you do this one more thing for me.</p> <p>Like depressed, well depressed is not the word, depressed is now like a clinical diagnosis, but kind of sad and despondent. He drops his head and puts his elbow on his knee and his fist on his forehead and drops his head.</p>	<p>And I'm like you know we all have bad, well I call them bad boo-boo days, we all have bad boo-boo days. We all have days where our bowels are runny or we have diarrhea and so we actually kind of make it a running joke in our house because my own bowel issues or when, I have some gastrointestinal issues like I have heartburn and some light lactose intolerance, I'm always like, "Oh hurry up I got to go to the bathroom." So he kind of like makes it a joke because after I eat I have to go to the bathroom maybe about an hour or hour and a half after I eat... So he always jokes and says your bowel program is worse than mine. So I think that kind of lightens that.</p> <p>Yeah. And then like he's had a couple, maybe I mean over the last several years only 4 bowel accidents over the last 3 or 4 years. So it doesn't happen often. He really gets upset when it happens or he really feels bad. He's apologetic and I'm like it's ok, it's not your fault. You didn't mean to do it. Like this is what I signed up for when I married you so this is what we do. So yeah, we make a lot of jokes about some things.</p>

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<b>VA-106</b>  Family 1 recipient Female White 69 Married/SO Para Comp BB No	NO REFERENCE	NO REFERENCE	Not associated with the spinal cord injury, no. He has distress, his memory issues that he's now having and he's aware of.	NO REFERENCE



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<b>VA-107</b>  Non-family >1 recipient Female Black 28 Not married Para Incomp BB Yes	NO REFERENCE	NO REFERENCE	<p>...he told me that he was in pain and it wasn't really nothing to worry about but I kind of saw a little distress in him. Like I said, he's (inaudible 0:13:42), you now and for him to be in a wheelchair for the rest of his life and he's paralyzed from his neck, his chest down, it gets frustrating for him and he's not able to do the things that he's used to doing and everything. He does stay pretty active. He does try to do as much as he can do but it was like that week, he was down, just didn't want to get up... That kind of made me worry a little bit. But the next week when I went to him, he was back in his good spirits and everything. We had a pretty good conversation...</p> <p>He just kind of gets upset because he's just kind of laying around. Any other time when I get there, he's already up, already cooked breakfast. He's already had his bath. He's ready to get his day started. When he don't have his clothes on already and when he's kind of moping around, I can tell the difference. He don't really tell me that he's frustrated and everything but I see the difference in that.</p>	<p>No. Everything is pretty much easy going there. When I walk in his home, I feel like I'm at home. He makes us feel very welcome there. Even some things that he don't ask me to do but I feel it needs to be done so I go ahead and go the extra step and do things anyway. He's appreciative to everything we do for him.</p> <p>Yes. That's when I get myself situated and get him to bed. He's normally in bed about 8 or 9 PM. Once I get him in bed, that's when I do my class work.</p> <p>He's a jolly guy. For him to be in the situation that he's in, he's having a lot, better than me personally, I wouldn't have been able to do it.</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>VA-108</b>  Family 1 recipient Female White 57 Not married Tetra Comp BB Yes	<p>There were a lot of things that I missed through the years with my family. We didn't live geographically close to my family. Or his, for that matter. I mean, they were all in Michigan, but it was about a three-hour drive. So if something was going on with the family, I didn't always go because I didn't want to leave him. In that way it was affected. We kind of planned around what he needed. That was the number one priority.</p> <p>I can't think of anything right up until his college graduation that we missed. I mean, we were just always there. Games, school events, pretty much anything we wanted to do with my son, we would do it. If a bowel or bladder issue did come up, we might not do it when we thought we were going to. But college graduation, [Redacted Proper Name] was in the hospital in Cleveland.</p>	NO REFERENCE	<p>He would get frustrated if the [inaudible: 19:58] device would break, of course. Because that would stop whatever activity he was involved with and we had to deal with that immediately. We would, you know, deal with it and move onto the next activity. He never stayed frustrated or depressed. His bowel program just worked like magic. We never had a problem with it until the last year, so it was never really an issue. He never even really got the flu or anything.</p> <p>And then he became very depressed, oh, I would say January of 2011 when we had to start running back and forth to the hospital all the time. Until then, he had not had really any medical issues. He'd had a couple of skin breakdowns that he had to go to the hospital for, but they cleared it up pretty quickly, as within three or four months. But about January we started having to rush him into the hospital because he was so sick, and they would keep him for a few days and send him home, and then he would get sick again and we'd go back.</p>	<p>The first year we were married, he was not working, and he would get very depressed over that.</p> <p>But yeah, you know, it did affect it. But I don't know that because he had a spinal cord injury and needed the bowel and bladder program, I don't know that it was any more of an issue than any other parent who starts to age or has health issues. You know, if he had had a heart condition and been in and out of the hospital we would have missed the same things.</p>

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<b>VA-109</b>  Family 1 recipient Female White 65 Not married Tetra Comp BB Yes	NO REFERENCE	<p>Well, being that I'm a nurse, I'm a caregiver anyway. And I just, I loved doing things for him. I love doing things for people. That's just part of who I am. And when I can't, it actually just this last month, my daughter just moved and I loved being over there, helping her every day. And it wasn't just because I got to see, I felt like I was useful. And I, you know, when [Redacted Proper Name] died, it was like I lost my best friend, I lost my job, I lost a good part of my income, and it was just ... I lost part of my identity because that's, you know. What do I do now? The days are just impossibly long. I really enjoyed taking care of him. I mean, sure there were the times I was a crank and I didn't, but it was more me. It was not him. It was never him.</p>	<p>[Redacted Proper Name] used to say sometimes he thought the worst part of being disabled was other people's reactions and not ... and they would expect him to be something other than a regular person. You know, expect him to be – well you may get the same thing if you're out with somebody – they would look at me, "Can he transfer? Can he do this? Can he do that?" He could speak for himself, you know. But he said sometimes, to him, the worst; he said he wished he could have been able to do it himself.</p> <p>He said that was probably the worst. I thought he would say that was the worst part of being disabled, but he said it was other people's reaction in that they wouldn't always give him credit for being an intelligent person that he was.</p> <p>Right. He said that was worse than not being able to take care of his own bladder and bowel.</p>	<p>It never bothered me doing it, being that I was a nurse... But he said, "I wish you didn't have to do it." I said, "Well, I would never have met you if we didn't have to do this kind of a thing!" So it was kind of a bittersweet thing. And he said, I can remember, he said, "I used to really hate Monday, Wednesday and Fridays, but once you became my nurse, I looked forward to it," because it meant he got to see me kind of a thing. And I looked forward to it too and that was how we met.</p> <p>I think there would be times when it was frustrating and not often, but if we'd gone through a rough path for whatever reason the catheter was blowing up or whatever, and I have a short fuse. [Redacted Proper Name] had patience of a saint and I'd always tell him, "It's not you. It's the situation." I never wanted him to feel like I thought he was a burden, because he never was to me. And I think that was always a worry, that he would think. Because he wasn't.</p> <p>That was always our part of the day that we knew we always had. No matter what the rest of the day was going to bring, that was our time together.</p>

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<b>VA-110</b>  Family 1 recipient Female Asian 63 Not married Para Comp BB Yes	NO REFERENCE	NO REFERENCE	<p>Semi-private. It was a semi-private, correct. And share with a young kid. And [Redacted Proper Name] had to do the bowel management. Oh, the kid was so ignorant. Say, "What that smell? What the fuck, that smell?" And then, "I gotta get out of here!" with his girlfriend. So we were so very, very embarrassed.</p> <p>Reality. If you understand a patient, you probably would take – and I understand. My kids understand. When he's doing that, he knew that they, he needed to do bowel movements, he didn't want anybody in the house. Because after a while, still smell.</p> <p>It's a crisis. And the smell. [Redacted Proper Name] was very clean person, and so he just hated. He just could not deal with that. And when he get angry like that, for himself – I don't know how to help him. I stay on the side. I look and talk and I can't say, "It's okay." I cannot do that.</p>	<p>It wasn't okay. And it wasn't just like somebody can come down, like a little kid. "Here's a Popsicle. Just have a Popsicle and you'll be fine." It wasn't like that, because you knew next moment it might happen again, and over and over. Right? And that was the thing for me was hard to see he could not deal with. And he was stressed, he was angry, and I don't know how to help him. And [inaudible: 31:31].</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>VA-115</b>  Non-family 1 recipient Female White 22 Married/SO Para Incomp BB Yes	NO REFERENCE	NO REFERENCE	<p>He kind of gets that winter depression, especially with this past winter being so cold, he maybe a handful of times left the house only because he had to go to a doctor's appointment or something. Other than that he was cooped up in the house, he didn't want to get sick...</p> <p>Yeah for the most part he's a very happy guy, especially with being in his condition for over half of his life. He's doing great. He does get worked up over little things that he can't control... But he just wants to kind of be in control as much as he can with everything in his life. Other than that he's a happy guy.</p> <p>Definitely. Once he's able to get out of the house and be more self-sufficient again, like normally he would go to the grocery store himself and he'd bring his dog and she'd help him get stuff off of the shelves... and over the winter he has to send his brother to do it. He can't just leave the house because he just wants to pick up a couple things at the store, he has to call his brother and make sure his brother can go to the store for him. He has to kind of rely on more people over the winter and that really kind of affects his mood.</p>	<p>I wonder sometimes, because he sees the same people every day. Not that they're not great people, I go in and tell him pretty much everything about my life just to hold a conversation with him so he knows what's going on. He has been really excited for me to have a baby. He had his brother make a bedside cradle for her and everything. And he has been really involved and loves to hear about it and everything. But I wonder when I'm gone for 10 hours during the day and when I come back at night if he has any visitors or if it was only his brother, that he might feel kind of lonely.</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>VA-117</b>  Non-family >1 recipient Male Black 52 Married/SO Para Incomp BB Yes	NO REFERENCE	<p>...the very first day that I went over there on my first assignment, I was like should I come back here again or not because I am doing these things and the wife is right there, same bed, while I'm cathing the guy and helping the bowel movement. I felt quite uncomfortable.</p> <p>Yeah, at first. Because I had never done that, I had done it in a facility but not in somebody's house. By then I said, ok I have to do it, very normal. So that's why I said if you build that relationship with the person you are caring for, thing become easy and very normal.</p>	NO REFERENCE	<p>...this one day he told me that when he was freshly injured that when things like why me, why me. I can't do this. But then he got over it. So he came to realize that this is now a part of my life and I have to deal with it. So whether I take it negatively or what, it's my life. So then there's a time I asked him, do you enjoy your life? He said he enjoyed his life. Then I said it's good that you enjoy your life because taking care of you and seeing you in your house with your wife and your kids has made me to understand life even more deeper.</p> <p>Because you have your wife and sexually you cannot do anything, but you're still married and you still love each other. I told him that changed my life again because some women would have left you or would have abused the relationship or he could have said I don't have anything, go your way, let me go my way. But you guys have stuck together, you are raising your kids together, you go on vacations together, you go out together. So I told him, I have learned a lot from you.</p>

Subject	Physical Accessibility	Psychological Adjustment & Coping (Caregiver)	Psychological Adjustment & Coping (SCI Participant)	Relationship with Care Recipient
<b>VA-118</b> Non-family >1 recipient Female White 22 Married/SO Tetra Incomp BB Yes	NO REFERENCE	I'm fine with it. At first I was not used to any of that sort of stuff, but you get used to what you're supposed to do so it's not too difficult anymore.	NO REFERENCE	NO REFERENCE